

**Scoping Study to explore the feasibility of a  
Health and Social Care Research and  
Development Network covering  
Black and Minority Ethnic Groups in Wales**

**Report submitted to the  
Wales Office of Research and Development  
Welsh Assembly Government**

**Published July 2005**

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## ACKNOWLEDGEMENTS

The study was funded by the Welsh Office of Research and Development (WORD). A total of one hundred and forty-two people took part in this study and we are grateful and thankful for the time they gave us. Twenty-three co-applicants who signed up to the study during the initial proposal phase provided guidance and support throughout the life of the study. The co-applicants gave their time freely and the Research team thanks them for the interest they demonstrated. I would like to especially thank the Research team. Their involvement ensured that the key deliverables were met. We also thank Jaynie Rance and Gillian Olumide, who analysed and drafted a detailed summary of a significant number of the stakeholder questionnaires.

Thanks to all!

Roiyah Saltus  
June 2005

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## **EXECUTIVE SUMMARY**

### **I. BACKGROUND**

This report provides information on the feasibility of establishing a Health and Social Care Research and Development Network covering Black and Minority Ethnic (BME) Groups in Wales. It also contains the findings of a scoping study to enhance research and development activity in this cross-cutting subject area, and recommendations on how best to establish a network. Both the scoping study and outline of the proposed network are rooted in the following core factors:

- The health and social care priorities of BME groups
- The health and social care priorities, and the mainstreaming of the equality strategy, of the Welsh Assembly Government
- Key priorities underpinning the Wales Office of Research and Development (WORD)
- The work and research priorities of BME voluntary health and social care organisations, as well as community groups and local, regional and All-Wales Equalities organisations
- The basic elements of network design

According to the 2001 Census, the number of people from BME backgrounds in the UK was 4.6 million (7.9 percent of the total population). In Wales, out of a population of approximately 2.9 million people (rounded down the nearest hundred), 2.1 percent were from BME backgrounds (61,600). This was an increase from 1.5 percent (41,551) recorded in the 1991 Census. Since 1991, there have been increases in the proportions of African, Indian, Pakistani, Bangladeshi, and Chinese people, and an increase in the number of people who classified themselves according to one of the several mixed ethnic groups used in the Census.

Although equality of access to healthcare and related social care/welfare on the basis of need was one of the founding principles of the NHS, at its establishment in 1948, health inequalities have continued to be an issue (Black et al. 1980). For many researching 'race', ethnicity and health, it is axiomatic that disparities exist within the health and social care system, with differences such as 'race', ethnicity, socio-economic status and geographic location impacting on the level of access to information and treatment, and on the utilisation, experience and satisfaction of health and social care provision. In the field of health and social care, complex arguments have been made about the balance between 'special' (meaning specific) needs, and entitlement to 'common' (or mainstream) services, for which minority ethnic people may have different levels of need (Chirico et al. 2000). The fact remains that, in general terms, BME people in the UK have shorter life expectancies and poorer physical and mental health. Again in general terms, the BME population is particularly disadvantaged as a result of discrimination and racism within society. Moreover, some must struggle with a health and social care system that is not yet adequately equipped to respond to their needs as increasingly required by statutory and legal obligations.

At fewer than 3 percent of the population, the number of people from BME backgrounds has grown, and will continue to grow. The diversity in ethnic groups and

culture, the history of settlement, the influx of new residents, and the dispersal of BME people across Wales present a considerable and multi-faceted challenge to health and social care local, regional and national services. The diversity of BME people's health and social care needs adds to this challenge.

## **II. AIMS AND OBJECTIVES OF THE SCOPING STUDY**

- To scope the current research and clinical practice activity taking place in this cross-cutting subject area, with particular attention to health and social care voluntary agencies, universities, local health boards (LHBs), equalities organisations and NHS Trusts, as well as existing health and social care networks
- To identify the perceived research priorities, the barriers to, and the opportunities for, developing this theme as understood by potential network members and their constituents
- To place the work of the proposed network in a wider context, by scoping the research and development activities of established UK networks and centres with a similar remit

## **III. METHODOLOGY**

*Objective 1:* To scope the current research and clinical practice activity taking place, by conducting Internet-based searches and making telephone enquiries, together with extensive networking with, and by, the co-applicants.

*Objective 2:* Canvassing of views via a short questionnaire. The data were collected via e-mail correspondence, telephone exchanges, and a series of meetings.

*Sample:* Purposive sampling. The co-applicants were asked to recruit respondents. Key BME voluntary organisations were also approached and asked to take part in this exercise, by sending questionnaires to their client groups and by holding small meetings.

*Objective 3:* To place the work of the proposed network in a wider context, by conducting an information review and sending out a short survey questionnaire.

## **IV. KEY FINDINGS OF THE SCOPING STUDY**

### **Current research activity**

'Stand alone' research activities account for the majority of current research activity. The 'stand alone' studies cover a number of areas in health and social care. In many cases, the studies conducted by universities covered a specific region. Not one all-Wales study with a fully representative sample of BME participants was found. There are ten research strands, covering the following areas of investigation (see Appendix 1 for summaries of the strands):

- Sickle cell and thalassaemia
- Diabetes
- 'Race', ethnicity and health
- Social policy, social welfare and political engagement
- The changing structures and processes affecting a range of health and social care organisations and user groups
- Multicultural education

- Social exclusion
- Ethnicity and society
- Islamic law and culture
- Chinese history and culture

### **Academics in Welsh Universities**

The dataset compiled during this exercise contains the details of 65 academics who had noted in their on-line profiles that they had an interest in this subject area. With regard to national health priorities, there is a high level of expertise in social policy, nursing, mental health and children's health, and in CHD and diabetes. The study provides indicators of a growing level of research interest in the area of haemoglobinopathies (sickle cell disease and the thalassaemias), as well as in the area of service quality and patient/user involvement. There is, however, a lack of research in the areas of learning and physical disability, the needs of Travellers, Gypsies and new migrant groups, and the impact of alcohol and drug misuse.

### **Local health boards and NHS Trusts**

It proved difficult to access information on the research activity and service/practice models and initiatives taking place in NHS Trusts, and time constraints and access problems resulted in very limited success. There was more success in collating information on similar activities taking place in LHBs. It is evident that some research is taking place, particularly in Cardiff, Swansea and Newport. Much more work is needed to provide a baseline of evidence regarding current activity in Welsh NHS Trusts and Local health boards (as well as in the social service departments of the twenty-two unitary authorities).

### **Voluntary Organisations**

Research is becoming an increasingly important activity for voluntary sector organisations. The review of voluntary agencies engaging in research in this subject area shows an increasing number of voluntary sector-university collaborations. Local health boards and health divisions of the Welsh Assembly are providing funding, as are UK funding bodies, primarily for fixed, 'stand alone' projects. If we were to base the network's research agenda on the health priorities highlighted by the work of national BME health and social care voluntary organisations in Wales, they would be as follows:

- Mental health
- Drug and alcohol misuse
- Children and chronic illnesses
- The health needs of women (including those suffering from domestic violence)
- Mainstreaming equality
- BME community development
- The health needs of asylum seekers and refugees

## Responses to the Stakeholder Questionnaire

One hundred and forty-two stakeholders returned completed questionnaires. The following questions were asked:

- What do you think are the key health and social care issues affecting BME groups in Wales?
- From the issues you have identified, please list them in terms of importance.
- What are the key challenges affecting research on the health and social care of BME people in Wales?
- We are seeking to establish a research group or network to take forward the issues raised in this questionnaire. What value would this be for your or your work? What would you want from such a network?
- How would you suggest we take this forward?

The responses to the questionnaire were grouped under a number of sub-headings. The key themes that emerged are summarised below.

Key issues include

- Illnesses throughout the life course
- The health of specific population groups (asylum seekers, travellers, children, older people, refugees, migrant workers, women)
- Broader determinants of health and well-being
- Access to services
- Service delivery and quality of care
- The role of equalities agencies and BME voluntary organisations
- Regional differences
- The importance of useful ethnicity data
- The welfare of children
- Importance of a R&D infrastructure

Key challenges include

- User involvement and public participation
- Effective community engagement models
- Sustained funding
- Workforce development and training (including the training needs of health and social care professionals)
- Mainstreaming of the equality agenda

What stakeholders wanted/expected from the proposed network include

- To be of value to BME patients, groups and communities in Wales
- Building up high quality research activity
- Effective dissemination strategies
- Engagement with BME patients and BME groups
- Access to information and resources
- Opportunity for joined-up working
- Service development

Stakeholders' suggestions on ways forward include

- Ongoing engagement and consultation



- Focus on key improvements to services
- Development of research infrastructure
- Clear strategies and transparent processes

## **Research and development activities of established centres and networks in the UK**

Five academic centres in England, and one in Scotland, are active in the field of ‘race’, ethnicity, diversity and health. A number of networks, unit or services also have a particular interest and track record of work of relevance to this proposed network. A short survey was sent to the centres, units and groups identified. The questions asked were as follows:

- Name of Centre / Role of Person responding.
- Main Organisational or Funding source of support for your Centre.
- What was the rationale for establishing this particular Centre or activity? (What is your ‘unique contribution’ or area of specialist interest?)
- What are the advantages and disadvantages of 'stand alone' or specialist units in research in the area of health and social care for minority groups?
- How do you make sure that research findings (and any other services you offer) are 'mainstreamed' and disseminated into UK policy and practice and equality debates?
- How have links (if any) been developed with BME patients, service users or groups?
- Do you have any “Best practice” guidance? If so, please attach it or indicate where to find it.

This scoping work was conducted by Professor Mark Johnson of the Centre for Evidence in Ethnicity Health and Diversity (CEEHD). His review points out that in England at present there is no established and centralised source of best practice guidance and evidence, or of established standards and professional support. Attempts at local and regional level in England to develop networks and establish groups in order to share information and best practice have in the past been short-lived. Only now are more sustained attempts being made to develop this field. This presents a unique opportunity for developing a network in Wales that is rooted in the needs of the Welsh population, but also has the potential to provide services and expertise on a UK-wide and international level.

## **V. FRAMING CONSIDERATIONS**

In summary, the scoping study highlights that at present research in this area in Wales is characterised by the following:

- An embryonic level of statistical ethnicity data currently available
- A moderate and increasing level of research activity rooted in the nation’s key health priorities, but as yet isolated
- An embryonic level of research activity specifically addressing ‘special concerns’ such as sickle cell disorders, the needs of refugees and asylum applicants (i.e., post traumatic stress disorders)
- A ‘critical mass’ of key stakeholders across the health and social care sector

- An increasing interest in research and development activity in BME specific, as well as ‘mainstream’ voluntary agencies
- An embryonic level of joined-up user, community and public engagement work
- No centralised support and information centre, unit, or service covering key health and social care concerns facing ethnic minority groups in Wales

The study makes clear that it would be timely and feasible to establish a network covering the health and social care needs of BME groups in Wales. Such a network would provide the necessary infrastructure and developmental work. It would allow for regional and All-Wales research to be reviewed and prioritised, in order to build on the plethora of local studies and needs assessments. It would provide a dedicated R&D context in which to link issues of ‘race’, ethnicity, and culture to the key biomedical, clinical, and health care research underway; and so broaden the knowledge base of appropriate clinical models and practice frameworks needed to care for diverse population groups.

This network presents an opportunity for a focused, co-ordinated and cross-sector programme of research and development, accessible by medical and health professionals, BME patients and members of the public, and by those in the voluntary health and equalities sectors, the local authorities and social services. A key activity of this proposed network must be to provide support to other research networks in order to build the overall knowledge base needed to improve the health and social well-being of BME people.

Empowerment and engagement must be key features of the proposed network. This will provide a unique opportunity to develop research methodologies, engagement strategies and user and public empowerment initiatives from the perspective of community development and empowerment. The voluntary health and social care sector, and community groups, will have a central role in developing and introducing these methodologies, strategies and initiatives. The differences among and between Black and minority ethnic groups make it most important to develop useful and relevant service user and public engagement methodologies and consultation models.

The initial period of consolidation and developmental work, which this network proposes to undertake, is a necessary first step. In the light of the above challenges, only *after* some of the developmental work proposed by this network has been carried out can the mainstreaming of equalities begin. The proposed network provides an opportunity to put in place a framework to address the health and social care priorities, needs, and experiences of BME populations in Wales, and to enable the health and social care service in Wales to provide, ultimately, the person-centred care they are striving to deliver.

## **VI. AN OUTLINE PLAN FOR DEVELOPING THE PROPOSED NETWORK**

### **Proposed Mission statement**

The proposed network will play a key role in promoting understanding about the needs and empowerment of BME populations in Wales through multi-disciplinary research, cross-sector partnerships, community engagement and the development and

implementation of multi-targeted promotion and dissemination strategies. It will provide the joined-up networking necessary for the cross-fertilisation of research activities and national health and social care priorities that are rooted in an All-Wales approach, and cognisant of UK-wide research and development priorities.

### **Stakeholder Groups**

The following key sectors and stakeholder groups will be invited to join the network: Welsh higher education institutions, NHS Trusts, Local Health Boards, service user and patient support groups, BME voluntary health and social care/welfare organisations and community groups, as well as key equalities organisations and services, including the CRE, Equalities Policy Unit (WAG), and the NHS Centre for Equality and Human Rights.

### **Proposed aims of the Network**

It is envisaged that the proposed network will establish a research and development programme rooted in the following six core aims:

1. **To establish a multidisciplinary research infrastructure** capable of identifying the health and social care priorities of BME patients, service users and groups in Wales.
2. **To develop high quality evidence-based research strands** with local, regional as well as All-Wales outputs. The strands to be developed will be rooted in the health and social priorities of BME populations in Wales.
3. **To give specific attention to, and make a substantial contribution to, BME community development and engagement** by working with groups to make improvements to their health and social well-being, and by proactively and systematically seeking improvements to their care in the health and social care sector. Equally important is the need to embed the work of this network in research methodologies that seek to build research capacity within BME community groups, in order to facilitate health improvements, foster empowerment and encourage higher levels of engagement with health and social care services.
4. **To give specific attention to the Welsh health priority areas and health improvement programmes** by offering a gateway for the exchange of information and for research collaborations with all the research networks, to ensure that the health and social care needs of BME patients, service users and groups are clearly evidenced in the research that is undertaken in all the networks.
5. **To utilise research findings to define practical solutions which assist both health and social care commissioners and service providers, BME patients, service users, community groups and organisations**, as well as other networks and key groups within the research and development infrastructure in Wales and beyond. This aim is rooted in the need to be able to make an informed contribution to the development of local, regional, national, UK and international policies that integrate research generated by the network into key public, private and voluntary sector health and social care practices and services.

6. **To ground all activities in an appropriate network model.** Rooted in this aim is the need to work proactively on the infrastructure of the research network, to ensure that it operates as an effective and important conduit of information related to the health and social care of BME groups in Wales.

## **INTRODUCTION**

The Wales Office of Research and Development (WORD) wishes to provide ‘start up’ funding for a number of research and development networks for health and social care in Wales. The aim of the networks will be to develop research activity in health and social care, and to enable Wales to initiate, and take part in, high quality large-scale research initiatives. In the context of health and social care, the term ‘network’ is often used to refer to a group of people, working in a co-ordinated manner across organisations and structural boundaries, who have a common agenda to promote health and social care improvements, and to reduce health and social care inequalities as they impact on particular population groups.

This report provides information on the feasibility of a Health and Social Care Research and Development Network covering Black and Minority Ethnic (BME) Groups in Wales. It contains the findings of a scoping study to enhance the research and development activity in this cross-cutting subject area. It also includes recommendations on how best to establish such a network.

Collaboration with a range of sectors remains a primary consideration, as evidenced by those who signed up as co-applicants, the targeted stakeholders, and those individuals and organisations that participated in the study. We hope that this report will contribute to the development of this subject in all these settings.

## **TERMS OF REFERENCE**

The issues that had to be addressed in the scoping study, as specified by WORD, were as follows:

- Justification for the choice of theme or sector
- A review of existing research and development activity in the field
- A view on the strengths and weaknesses of the research and development activity and structures covered by the review
- An outline of plans for developing a research and development network in the chosen field
- An explanation of how the proposed network would enhance research and development activity in this area
- An account of how the proposal fits with Welsh Assembly Government priorities for health and social care
- An account of how the proposal fits with the work of the UKCRC
- A verbal presentation of the findings, to be made to Welsh Assembly Government officials at some point in May 2005

## **1 NOTE ON TERMINOLOGY**

- 1.1 Research has shown that the terminology used to describe different ethnic groups—not least those that have been racialised, marginalised and/or oppressed—is fraught with difficulties (Saltus 2002). We accept that the terminology we use cannot preclude the importance of people’s self-definition.
- 1.2 In the UK, the terms ‘minority ethnic’ or ‘ethnic minorities’ are most often used to refer to all minority groups of the population not indigenous to the UK that hold cultural traditions and values derived, at least in part, from countries of their or their ancestors’ origin.
- 1.3 The term ‘black’ is often used not to differentiate black minority groups from other minority ethnic groups, but rather to ensure that the continuing impact of the legacy of racism remains highlighted and is made problematic.
- 1.4 The term ‘black and minority ethnic’ (*BME*) people, populations and groups will be used in this report, with key minority ethnic groups taken as those included in the UK census classification system (Table 1).
- 1.5 This term, however, includes gypsies and travellers (variously described as Gypsies, Travellers, Romanies or the Romani people), who also have a distinct culture, as defined in the Race Relations Act (1976); but they were not (as were some other visible and ‘invisible’ BME groups) listed in the census classification system. These groups comprise English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers and Irish Travellers, each of whom has a separate ethnic identity that is particularly evident in their different languages; but they share many aspects of a common cultural identity as traditional Travellers or Romani people.
- 1.6 It is axiomatic that BME populations are heterogeneous, with differences both within and between groups.

## **2 WALES’ BLACK AND MINORITY ETHNIC (BME) POPULATIONS**

- 2.1 According to the 2001 Census, the number of people from BME backgrounds in the UK was 4.6 million (7.9 percent of the total population). In Wales, 2.1 percent (61,600) of a population of approximately 2.9 million people (rounded down to the nearest hundred) were from BME backgrounds, an increase from 1.5 percent (41,551) in the 1991 Census. Since 1991, there have been increases in the proportions of African, Indian, Pakistani, Bangladeshi, and Chinese people, and an increase in the number of people who classified themselves according to one of the several mixed ethnic groups used in the Census.

**Table 1 The Ethnic Group composition of the population of Wales**

<i><b>Ethnic group</b></i>	<i><b>percentage of total population (n=2,903,085)</b></i>
White British	95.99
White – Irish	0.61
White – Other	1.28
Mixed – White and Asian	0.17
Mixed – Other mixed	0.15
Mixed – White and Black African	0.08
Asian – Pakistani	0.29
Asian – Indian	0.28
Asian – Bangladeshi	0.19
Asian – Other Asian	0.12
Black – African	0.13
Black – Caribbean	0.09
Black – Other Black	0.03
Chinese	0.22
Other ethnic group	0.18

- 2.2 In Wales in 2001, more than 25,500 people were of South Asian descent, the majority being Indians and Pakistanis. Nearly 18,000 people were of mixed ethnic origin (described as White and Black Caribbean, White and Black African, White and Asian and other mixed). In 2001, 8,600 people described their ethnic group as Black, with a further 6,100 being of an African (including mixed White and Black African) background. In 2001, 6,000 people described their ethnic group as Chinese. The Indian and Pakistani ethnic groups were the largest individual minority groups, each comprising 8,300 people, but many individual minority ethnic groups have populations of a similar size, between 5,000 and 7,000 people. The minority ethnic population is therefore culturally diverse, with no dominant minority group (WAG Statistical Directorate 2004).
- 2.3 Under-enumeration remains a concern when making use of Census findings, not least in relation to new or transient populations (e.g., students, migrant workers, refugees, or traveller groups). Important here is the dispersal policy underpinning the processing and settlement of asylum seekers in Wales. Although not necessarily included in the Census, the number of new residents from BME backgrounds seeking asylum is increasing—in the cluster areas of Cardiff, Swansea, Newport and Wrexham in particular. In the past decade, the ten main countries of origin of principal asylum applicants to the UK have been, in descending order, Somalia, Iraq, Sri Lanka, Afghanistan, Turkey, Pakistan, China, India and Iran. These countries account for over half (53 percent) of all asylum applications. In the last two years, an increasing number of people have sought asylum from Pakistan, India and the Democratic Republic of the Congo (DRC, formerly Zaire). According to figures published

in December 2003, there were over 5,000 asylum seekers in Wales (WAG 2004a).

- 2.4 In Wales Gypsies and Travellers groups live on both official and unofficial sites. These groups are roughly split into traditional Travellers and New Travellers. In Wales, the last caravan count was conducted in 1997 by the Welsh Office, which counted 732. In 1998, Save the Children Fund conducted a count and found 2,000, over twice the Government's figure (WAG 2000).
- 2.5 The BME population of Wales is highly concentrated geographically. Cardiff, Newport, Swansea, Rhondda Cynon Taff and the Vale of Glamorgan contain nearly 70 percent of the minority ethnic population. By far the highest concentrations are in Cardiff, with approximately 25,700 people from BME backgrounds. The BME population in the remaining local authorities is fairly evenly distributed (2.1 percent is the Welsh national average). In a recent interrogation of the 2001 Census, Williams et al. (2004) state that, in north Wales, the total minority ethnic population is one percent (6,697), a 60 percent increase since the 1991 Census. Those of 'mixed ethnicities' comprise the largest grouping, followed by Chinese, South Asian groups (Indian, Pakistani, Bangladeshi and 'Other Asian'), and then Black and Black British.
- 2.6 Wales has a long history of minority ethnic settlement, concentrated mainly in the south Wales coal ports, but with pockets of settlement throughout Wales. The histories, settlement patterns, residential status and occupational profiles of BME groups in Wales are different from those elsewhere in the UK (Williams et al. 2003). There is a need, therefore, to consider the particularities of the Welsh context when examining the health and social care of BME groups.
- 2.7 Moreover, there is a need to consider the particularities of BME populations in different parts of Wales. For instance, isolation from networks of support is a key concern in north Wales and in rural parts of Wales, but not necessarily in south Wales. The impetus to develop more responsive services may also be stronger where there is a higher proportion of minority ethnic groups, although statutory requirements demand that, even where there are small numbers of BME people, their health and social care needs must be met (Williams et al. 2004).
- 2.8 Caution is also needed when seeking to examine specific regional areas in Wales: it is necessary to be aware of the particulars both between and within the three main geographical areas. For instance, the six counties of north Wales should be treated as a composite geographic entity in terms of the position of BME people and communities only with caution, because north Wales 'encompasses considerable diversity in socio-economic terms ranging from the predominately rural, agricultural and under-populated areas of Ynys Mon, Gwynedd and south Conwy, through the tourist towns along the length of the north Wales coastline, to the industrial east of Flintshire and Wrexham' (Williams et al. 2004:10).



### **3 THE HEALTH AND SOCIAL WELL-BEING OF BME PEOPLE – AN OVERVIEW**

- 3.1 Although equity of access to healthcare and related social care/welfare on the basis of need was one of the founding principles of the NHS at its establishment in 1948, health inequalities have continued to be an issue (Black et al. 1980).
- 3.2 For many researching ‘race’, ethnicity and health, it is axiomatic that disparities exist within the health and social care system: differences such as ‘race’, ethnicity, socio-economic status and geographic location impact on the level of access to information and treatment, and on the utilisation, experience and satisfaction of health and social care provision.
- 3.3 These disparities must be seen against a backdrop of increased risk of ill health. Although research shows that BME groups are diverse in terms of socio-economic status, language, generation, culture and lifestyles (a diversity which is reflected in their health status, disease patterns and health behaviour), it is clear that a disproportionate number of people from BME backgrounds are at an increased risk of a range of chronic illness, including diabetes, coronary heart disease, strokes and cancer (Smaje 1995, Acheson 1998). BME people are also at an increased risk of chronic illnesses such as sickle cell disease and thalassaemia (Anionwu & Atkins 2001).
- 3.4 As the recent Department of Health report *HIV and AIDS in African Communities. A Framework for Better Prevention and Care* (2005) highlighted, HIV and AIDS have disproportionately affected African communities in England. After gay men, this group is the largest group affected by HIV, and since 1999 new diagnoses in Africans have overtaken new diagnoses in other groups.
- 3.5 The Traveller community suffers significantly lower levels of good health than the permanently settled wider population, with the community’s health status amongst the poorest for minority ethnic groups. The reasons for this are the same as for other minority ethnic groups: they include poverty and unemployment but there are also added factors such as their living conditions. The living conditions for some can be poor, and include lack of water and sanitation, poor nutrition and increased risk of accidents (Hennick 1993). Poor environmental conditions in many sites lead to greater risks of chronic conditions, such as respiratory disease, rheumatism and digestive illness. Their level of infant mortality is the highest of all ethnic groups, as is the mortality rate of this group as a whole.
- 3.6 How individuals from different minority ethnic groups use and experience services is as much a product of their own beliefs, needs and expectations as it is a product of the attitudes and perceptions of service providers. Stereotypical views of BME people, racism, and cultural ignorance can undermine how health and social care services assess and respond to minority ethnic patients and clients.

- 3.7 Asylum applicants and refugees are known to be a multi-ethnic group that is disadvantaged in terms of access to healthcare and social services. Reduced access to social care support, language difficulties, lack of cultural competence amongst health and social care staff, changes to UK asylum legislation, and difficulties in settling contribute to this group's marginalised position in UK society. There is an argument for considering the health needs of asylum applicants and refugees separately, because of the additional factors that have to be taken into consideration, such as the effects of war, displacement and torture. These factors can lead to mental and physical trauma, incomplete immunisation of minors, a history of poor diet and nutrition, and problems in gaining employment that are markedly different from those experienced by BME people who were born in the UK or who are established residents.
- 3.8 Migrant workers are also known to be a multi-ethnic group that is disadvantaged in terms of access to healthcare and social services. Reduced access to social care support, language difficulties, lack of support from contracting agencies, housing and childminding difficulties, and difficulties encountered when managing short-term (and often mobile) contracts are all contributory factors impacting on their care. Other factors include the health and safety hazards associated with the unscrupulous employment practices with which some migrant workers have to contend.
- 3.9 Health can never be seen in isolation from social determinants. Overall, health and life expectancy are still linked to social circumstances and childhood poverty. Despite improvements, the gap in health outcomes between those at the top and bottom ends of the social scale remains large, and in some areas it continues to widen. These inequalities mean poorer health, reduced quality of life and early death for many people. Given that Wales has some of the most economically deprived areas in Europe, and that the link between poverty and ill health is well documented, there is evidence to suggest that Wales' minority ethnic communities face similar, if not increased, levels of deprivation and social exclusion, albeit with some significant regional differences (Williams et al. 2004, *Cardiff Health, Social Care and Well-Being Strategy* 2005).<sup>1</sup> In highlighting these regional differences, the fact remains that a significant number of people from BME backgrounds throughout Wales are enduring social deprivation and exclusion that, in turn, have an impact on the quality of their health and social well-being.

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<sup>1</sup> Recent research conducted in North Wales found that caution has to be used in north Wales in particular in assuming the link between disadvantage and BME people. Moreover, due to the dispersed nature of the BME population, very few people live in Community First areas. Thus, a long-term regeneration programme targeting deprivation and social exclusion can only have a limited impact in north Wales in addressing the needs of BME in the region who are facing enduring deprivation and exclusion.

- 3.10 There are complex arguments about the balance between ‘special’ (meaning specific) needs and entitlement to ‘common’ (or mainstream) services, for which minority ethnic people may have different levels of need (Chirico et al. 2000). In general terms, however, BME people in the UK have shorter life expectancies and poorer physical and mental health. Moreover, some must struggle with a health and social care system that is not yet adequately equipped to respond to their needs, as increasingly required by statutory and legal obligations. At fewer than 3% of the population, the number of people in Wales from BME backgrounds has grown and will continue to grow. The diversity in ethnic group and culture, the history of settlement, the influx of new residents, and the dispersal of BME people across Wales present a considerable and multi-faceted challenge to health and social care national, regional and local services. The diversity of their health and social care needs adds to this challenge.

### **The BME Voluntary health and social care sector in Wales**

- 3.11 The origins of many BME voluntary organisations in Britain are to be found in large-scale migration from the Caribbean and Asian Subcontinent in the 1950s and 1960s. Originally, these organisations provided basic support for immediate needs, such as accommodation and employment (McLeod & Owen 2001). This evolved to cover larger areas of service provision, and BME voluntary organisations came to provide marginalised groups with a wide range of services. Within this context, BME voluntary bodies perform four major functions: overcoming social isolation, affirming values and beliefs, doing social and pastoral work for their clients, and acting as quasi-unions defending the interests of their members (Rex 1991, McLeod & Owen 2001).

In Wales, a number of BME health and social care/welfare voluntary organisations seek to address the needs of BME people. From the scoping exercise, it is clear that research is increasingly important to the work of BME voluntary organisations, and that the majority of these organisations are also working in collaboration with universities. A mapping study undertaken by the Council for Ethnic Minority Voluntary Sector Organisations (CEMVO), in September 2002, revealed that there are 136 BME voluntary sector organisations across Wales, of which over 40% are faith-based. The findings also indicated that most BME voluntary sector organisations are concerned about their sustainability, particularly as a result of lack of access to core funding activities and lack of official recognition. Given the important role these organisations perform, this presents another set of challenges that any network, organisation or service seeking to work with BME groups will have to address.

## **4 EQUALITY AND THE WELSH ASSEMBLY GOVERNMENT**

- 4.1 As laid out in its recently published *Race Equality Scheme* (2005), the Welsh Assembly Government has a statutory duty to ensure that equality of opportunity is embedded in its work, as outlined in the *Government of Wales Act* (1998):

*The Assembly shall make appropriate arrangements with a view to securing that its functions are exercised with due regard to the principle that there should be equality of opportunity for all people. (Section 120)*

4.2 According to the Welsh Assembly Government's Race Equality Scheme, the Assembly will pursue a number of aims to achieve its race equality vision and fulfil its statutory duties to promote race equality. These aims include the following:

- Develop policies and deliver services in a way that takes account of the needs of different ethnic groups in Wales and does not racially discriminate
- Actively promote equal opportunities for all ethnic groups
- Promote good race relations in Wales
- Help build the capacity of minority ethnic groups so that they have the confidence to engage with the Assembly and gain access to services and information with ease

4.3 To achieve these aims, the Assembly Government has set objectives which reflect the relevance and priority of its policy areas to race equality. These objectives include the following:

- Re-test its policies and programmes for their relevance to the general duty of the Race Relations Act
- Support people from all ethnic groups to live healthy and independent lives; work to eliminate unlawful discrimination; and promote good race relations in NHS and social care settings
- Promote good quality housing for all ethnic groups
- Assist refugees successfully to integrate in Wales and promote a positive image of refugees and asylum seekers
- Address the discrimination and disadvantage faced by Gypsies and Travellers

4.4 In the longer term, the Assembly aims to incorporate its Race Equality Scheme into an overarching Mainstreaming Equalities Strategy that will integrate an equalities dimension into policy planning, decision-making, implementation and evaluation. This should lead to a better understanding of the diverse needs of the different ethnic groups in Wales, and to the development and delivery of policies and services that are responsive to those needs.

### **The Wales Office of Research and Development (WORD)**

4.5 The challenges facing the health and social care services are great. They include

- Addressing the multiple threats to the health and social well-being of a diverse population
- Continuing to develop the complex interventions that are required to tackle any one aspect of ill health
- Grounding practice and policy in evidence-based research

- Evaluation of users' differential experience of services

According to key WORD policy documentation, research and development should be viewed as central to the development of health and social care services. There are some major strengths to be built on, and there are gaps that need to be addressed (2002).

The first four sections of this report have provided the background and context of the study. The next section will explore in greater detail the need for, and the feasibility of, establishing a network covering the health and social care needs of BME groups in Wales.

## **5 THE HEALTH AND SOCIAL CARE RESEARCH AND DEVELOPMENT NETWORK COVERING BME GROUPS IN WALES**

### **Background**

5.1 The main driver for this proposed R&D network is the present dearth of evidence-based research on the health and social care priorities, needs, and experiences of BME populations in Wales. It is important to note that some significant initiatives and programmes are underway. For instance, in the recently published document, *A statistical focus on ethnicity in Wales* (WAG 2004), the key findings of the health issues facing BME groups as taken from the 2001 Census are detailed, and provide a 'snapshot' of their health needs.

5.2 Moreover, this R&D proposal is shaped by key themes, strategies and frameworks developed in the health and social care services, and in the voluntary services. These are, in turn, rooted in policies emanating from the health and social care research and development divisions of the Welsh Assembly Government. These themes, strategies and frameworks highlight the Welsh Assembly Government's commitment to

- Developing the nation's health and social care services
- Ensuring that the Voluntary Sector is at the heart of National Assembly policy
- Ensuring that proposed policy and action is informed by clear research directives
- Developing an equitable health and social service underpinned by closer inter-agency work and client collaboration<sup>2</sup>

With these policy directives have come national initiatives such as the Inequalities in Health Fund (IIHF), the Sustainable Health Action Research

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<sup>2</sup> Key documents include: *Voluntary Sector Scheme* (WAG 2000); *Adult Mental Health Services. A National Service Framework for Wales* (WAG 2002); *A Health and Social Care Research and Development Strategic Framework for Wales* (WAG 2002); *The Secondary Health Care Needs of Ethnic Minority Communities in Wales* (Ethos, 2003); *Annual Report on Social Inclusion in Wales* (WAG 2002); *Well-Being in Wales* (WAG 2002); *Challenging the myth: 'They Look After Their Own' – Carers' Services: Access Issues for Black and Minority Ethnic Carers in Wales* (WAG 2003); and *Health, Social Care and Well-Being Strategies* (WAG 2004).

Programme (SHARP), and Communities First (an area-based regeneration programme). These initiatives have contributed to tackling determinants of health and social inequalities in general (across all ethnic groups), addressing diseases that most adversely impact on the health of BME populations, and tackling social and economic stressors in some of Wales' most deprived areas.

- 5.3 In addition, recent university-based studies have addressed the health information needs of minority ethnic groups (University of Wales, Swansea); BME people's access to fertility services (University of Wales, Swansea); the health promotion needs of BME groups in Wales (ASERT Programme – Middlesex University); the mental health information and treatment needs of BME groups in Cardiff (BE4 Study, University of Glamorgan); the health and social care needs of unaccompanied children seeking asylum (a collaboration between Cardiff University and University of Glamorgan); the physical health care needs of BME communities (University of Wales, Swansea), and BME communities' needs and experiences in accessing legal and related social welfare advice services (a collaboration between University of Wales, Bangor and the University of Glamorgan). There has also been the work supported by the Care Council for Wales, such as *Working with Difference (Gweithio Gyda Gwahaniaeth)*, a training resource for social care practitioners that addresses race equality issues, and was written by Charlotte Williams (University of Wales, Bangor) and Cherry Short (Commission for Racial Equality).

### **Why is there a need for a network dedicated to covering the health and social care needs of BME groups in Wales?**

- 5.4 Despite the important developments outlined above, much more research and development work remains necessary in the area of BME health and social care in Wales. In his recent systematic review, Peter Aspinall identified the major gaps in national Welsh studies (such as the Welsh Health Surveys) and the unreliability of ethnicity data (such as Patients' Episode Database for Wales – PEDW) in highlighting the needs of BME groups (Aspinall 2003). The statistical data needed to build an understanding of BME health and social care needs, and to monitor the access and utilisation of available services, remains embryonic.
- 5.5 In her review, entitled 'Health, Well-being and Access to Health and Social Care of Selected Minority Groups' (2004), Vivienne Walters highlighted the apparent lack of information and access to care of BME populations in Wales. Key issues of concern included the lack of appropriate information, language barriers, culturally alien services, and institutional discrimination – issues that are mirrored by the research findings of studies conducted elsewhere in the UK (Lloyd & Moodley 1992, Modood et al. 1997, Arai & Harding 2002). The regional and Wales-wide qualitative studies necessary to generate the data that will detail the quality and experiences of service provision of BME groups have yet to be conducted.
- 5.6 In regard to the wider determinants of health, there are gaps regarding poverty, health and social well-being. The Child Poverty Task Group was set up by the Welsh Assembly in 2004, to review existing information on the root causes and

significant determinants of child poverty in Wales. It reported that there were insufficient data available on the circumstances of particular ethnic groups as related to key poverty indicators.

- 5.7 The issues involved in how best to involve specific minority ethnic groups in health and social care partnerships (i.e., pregnant asylum seekers, BME youth, migrant workers, people from BME backgrounds living in rural areas and BME people with learning difficulties) have yet to be tackled on a regional or All-Wales level.
- 5.8 Pockets of knowledge exist, but there has yet to be a co-ordinated all-Wales research strategy dedicated to improving the health and social care of BME groups in Wales.
- 5.9 Even though the health and social care needs of BME groups are increasingly being highlighted as a research priority within the various divisions of the health and social care sector, at present there does not exist a body, unit or network that can provide expertise and support from a multi-disciplinary perspective.
- 5.10 In order to mainstream equality in Wales' integrated health and social care services successfully and sustainably, it is important to undertake this developmental work. This network presents an opportunity for a focused, co-ordinated and cross-sector programme of research and development, dedicated to issues of 'race', ethnicity, health and social care in Wales. This programme can be accessed and used by medical and health professionals, BME patients and members of the public, and by those in the voluntary health and equalities sectors, the local authorities and social services.
- 5.11 This brief overview makes clear that establishing a network covering the health and social care needs of BME groups in Wales is necessary and timely. What is needed is the infrastructure and developmental work that the network model can offer.

## **6 THE SCOPING STUDY**

- 6.1 The aim of this scoping exercise was to enhance the research and development activity in the proposed theme. The objectives of our programme of investigation were as follows:
  - *To scope* the current research, clinical and practice activity taking place in this subject area, with particular attention to health and social care voluntary agencies, universities, local health boards (LHBs), equalities organisations and NHS Trusts, and existing health and social care networks
  - *To identify* the perceived research priorities, the barriers, and the opportunities for developing this theme, as understood by potential network members and their constituents

- *To place* the work of the proposed network in a wider context, by scoping the research and development activities of established UK centres, units and networks with a similar remit

## 6.2 Methodology

*Objective 1:* Internet-based searches and telephone enquiries, together with extensive networking with, and by, the co-applicants.

*Objective 2:* Canvassing of views via a short questionnaire. The data were collected via email correspondence, telephone exchanges, and a series of meetings following a consensus approach.

*Sample:* Purposive sampling. The co-applicants (N=23) were asked to recruit respondents. Key BME voluntary organisations were also approached and asked to take part in this exercise, by sending questionnaires to their client groups and by holding small meetings and focus groups.

*Objective 3:* Information review and synthesis, conducted by the Centre for Evidence in Ethnicity, Health and Diversity (CEEHD), De Montfort University. This included the canvassing of views via a short survey.

## 6.3 Contributors to this study

The following is a list of organisations who were made aware of this study and who made a contribution to, or took part in, the study:

African Community Centre (Swansea)  
 Age Concern Swansea  
 Barnardos, Cardiff  
 Cardiff NHS Trust  
 Cardiff Sickle Cell and Thalassaemia Centre  
 Carers Centre, Cardiff  
 Commission for Racial Equality, North Wales Office  
 Diabetes UK Cymru  
 Filipino Association  
 Gwynedd Council  
 Isle of Anglesey County Council  
 Minority Ethnic Women's Network, Swansea  
 Newlink Wales  
 NHS Centre for Equality and Human Rights (formerly the NHS Wales Equality Unit)  
 NHS Direct Wales  
 North Wales Housing Partnership  
 North Wales Local Health Board  
 North Wales Race Equality Network (NWREN)  
 Performance and Strategic Planning, County Hall Swansea  
 Philipino Centre (Swansea)  
 Shekina Multi-Cultural Women's Group (North Wales)  
 Swansea Council for Voluntary Services Swansea Social Services Department  
 Swansea LHB  
 Swansea Social Services Department  
 Trust Nurse Executives across Wales  
 Welsh Refugee Council



#### 6.4 Data collection

*Objective 1:* An Internet-based search of research activity in Wales' higher education institutions was conducted, with particular attention to schools of nursing and medicine, and to universities developing social work programmes. Local Health Boards and NHS hospitals linked to higher education institutions were also contacted concerning relevant local initiatives and projects, clinical practice models and current research activity being developed or undertaken by staff.

*Objective 2:* In the first stage, the research team developed a short questionnaire. This questionnaire was piloted with the co-applicants. In the second stage, the co-applicants and targeted stakeholders disseminated the six questions to their networks and client/service user groups via meetings, email correspondence, and telephone exchanges. The questions revolved around the following themes:

- The health and social care research issues
- The health and social care research priorities
- The challenges to research
- The opportunities in developing this particular research theme
- Ways forward

One hundred and forty-two stakeholders completed questionnaires. When all the data had been collected, three consensus focus groups were held in Bangor, Cardiff and Swansea. The aims of the consensus focus groups were as follows:

- To provide the opportunity for co-applicants to present and summarise the answers given in the questionnaires, allowing those who canvassed views to present their views, as well as the views they collated
- To provide the opportunity for invited stakeholders to give their views on the issues raised in the questionnaires
- To work with the group in order to reach a consensus regarding the key points raised in the questionnaire returns and in the focus group discussion
- To record key issues, raised in the focus group discussion, that needed to be considered further
- To provide the opportunity for attendees to scope 'next steps'

Time constraints meant that the questionnaire was very short and the analysis was conducted very quickly. All possible attempts were made, however, to provide a meaningful analysis of the questionnaires. One final meeting was held in order to summarise key findings.

*Objective 3:* In order to place the work of the proposed network in a wider context, CEEHD compiled a listing of the principal centres and networks concerned with the health and social care of BME groups in other parts of the UK. A scoping review of the research activity of a selection of UK higher education institutions and NHS trusts was conducted, and documentation collated from each identified centre. The short survey was conducted, and the

data collated, by e-mail correspondence and telephone exchanges. The topics addressed in this scoping review were as follows:

- The rationale for establishing the particular centre or service
- The advantages and disadvantages of 'stand alone' or specialist units
- How key services and research findings are 'mainstreamed' and disseminated (with particular focus on the links with UKCRC and UKCRN)
- How links with BME patients, service uses and groups have been developed

6.5 The next three sections of this report detail the findings of the scoping study. Like most scoping exercises, it has a limitation that may be obvious but should be noted: the results are indicative, rather than exhaustive. What follows is an indication of the research currently being undertaken, based on the questionnaires that were sent out, the focus groups and small meetings that were organised, and the scoping work conducted via the Internet, with some follow-up telephone calls and email exchanges in March and April 2005. More research is necessary, but taken together the following findings remain, nonetheless, a useful 'snapshot'.

## **7 RESEARCH ACTIVITY IN WELSH UNIVERSITIES, NHS TRUSTS, LOCAL HEALTH BOARDS AND VOLUNTARY ORGANISATIONS**

*Objective One:* To scope the current research, clinical and practice activity taking place in this subject area, with particular attention to health and social care voluntary agencies, universities, local health boards (LHBs), equalities organisations and NHS Trusts, as well as existing health and social care networks.

### **Welsh Universities**

- 7.1 The integration of health and social care in Wales is an implicit acknowledgement of the need to link health with social determinants, and to approach improvements to health and social well-being from a holistic, multi-variable perspective.
- 7.2 Since the integration into Welsh universities of NHS education services for health care professions, teaching in all areas of healthcare has developed and expanded. The more recent establishment of three-year Social Work degrees in Wales, together with a number of related degrees in Voluntary and Community Studies, has ensured that the level of teaching in all areas of health and social care will continue to increase the number of highly qualified practitioners and professionals, and continue to improve the quality of service offered in Wales' health and social care sectors. Table 2 shows the emerging framework in which the health, social care and related needs of BME people can be explored by a range of disciplines.

**Table 3 Teaching in core subject areas in Wales' higher education institutions**

<b>Field(s) of teaching</b>	<b>University</b>	<b>School/ centre/department</b>
<b>Nursing, Midwifery and Health Studies</b>	Cardiff University Cardiff University North East Wales Institute University of Glamorgan UWIC University of Wales, Swansea University of Wales, Bangor	School of Nursing and Midwifery Studies Health Care Studies  Nursing School of Care Sciences Healthcare Studies School of Health Science School of Nursing, Midwifery and Health Studies
<b>Medicine</b>	Cardiff University University of Wales, Swansea University of Wales, Bangor	School of Medicine School of Medicine Clinical School
<b>Social Work</b>	Cardiff University North East Wales Institute  University of Glamorgan UWIC  University of Wales, Bangor University of Wales, Newport University of Wales, Swansea	Department of Social Sciences Department of Social Welfare & Community Justice School of Care Sciences School of Health and Social Sciences School of Social Sciences School of Social Studies Department of Applied Social Sciences
<b>Voluntary and Community Studies</b>	University of Glamorgan  UWIC University of Wales, Newport University of Wales, Lampeter	Programme for Community Regeneration Youth and Community Studies Department of Social Sciences Department of Voluntary Sector Studies
<b>Ethnicity, Culture and Religion (as related to BME Studies)</b>	Cardiff University  University of Wales, Lampeter University of Wales, Lampeter University of Wales, Swansea	Centre for the Study of Islam in the UK Centre for Islamic Law & Culture Centre for Chinese Studies Masters in Cultural Awareness (MScEcon) Department of Sociology and Anthropology

### **Research activity taking place in Welsh universities**

7.3 The teaching of core subject areas in Welsh universities points not only to an identifiable teaching base in place in order to achieve the goal of high quality integrated health and social care. It also acts as a marker, or indicator, of the research activities taking place, and the potential for conducting research in this cross-cutting, multi-disciplinary theme.

7.4 In the Internet search of current research activity taking place in Welsh universities, the following inclusion criteria were used:

- Biomedical and clinical research
  - Nursing, midwifery and allied health care research
  - Social science research (key sub-subject areas: sociology, social studies, cultural studies, social policy)
  - Life-long learning (this area was chosen because of its established practice of innovative and creative teaching and research activities, and the emphasis on non-traditional learning pathways, and on students from a range of backgrounds)
  - Academics who highlighted 'race' ethnicity, multiculturalism or societal inequalities as significant or notable research interests in their staff profiles
  - Academics with publications rooted in or linked to the themes underpinning the work of this proposed network
- 7.5 In analysing the data collated, research activity was divided into three broad categories: research centres, research strands and 'stand alone' research activities. There are no research centres or units in Wales. There are ten research strands within research units, centres and departments.
- 7.6 The ten research strands cover the following areas of investigation (see Appendix 1 for short summaries of the strands):
- Sickle cell and thalassaemia
  - Diabetes
  - 'Race', ethnicity and health
  - Social policy, social welfare and political engagement
  - The changing structures and processes affecting a range of health and social care organisations and user groups
  - Multicultural education
  - Social exclusion
  - Ethnicity and society
  - Islamic law and culture
  - Chinese history and culture
- 7.7 'Stand alone' research activities account for the majority of research activity. The 'stand alone' studies cover a number of areas in health and social care (please refer to sections 5.3 & 5.4 of this report). Other recent studies that were found include
- *Genetics, Religion and Identity*: an interdisciplinary study that will investigate how Bangladeshi Muslims in Britain transmit information about genetics across different generations and make decisions about genetic testing, especially in relation to health care and religious professional opinion (Cardiff University)
  - *Families and Migration: Older People from South Asia* (University of Wales, Bangor)
  - *Race and Ethnicity Access to Learning Study* (2003-2005) (University of Glamorgan)
  - *The Experience of Black and Minority Ethnic Children Living in the South Wales* (Cardiff University)

- *Infant Feeding Patterns in the Syhetti Speaking Community in Cardiff* (Cardiff University)
- *European Study of Adult Well-Being* (includes culture as a key variable) (University of Wales, Bangor)
- A qualitative study to explore Bangladeshi Women's knowledge and experience of the menopause (2003-2005) (University of Wales, Swansea)
- Research into Ethnic Minorities in Monmouthshire (Cardiff University)

7.8 The dataset compiled during this exercise contains the details of 65 academics who indicated in their on-line profiles that they had an interest in this subject area. As with the other exercises undertaken, a broad view of health and social care was taken, and the academics identified were based in departments across the spectrum of social care, health and humanities sub-disciplines. Based on the profiles, their research interests include

- Immigration and identity
- Racism, discrimination and disadvantage
- Welsh nationalism and national identity
- Ethnic minorities and the labour market
- Religion, health and spirituality
- Children's rights, autistic spectrum disorder and children in deprived circumstances
- Special interest: Patients - ethnic minorities - diabetes, breast-feeding, CHD
- Race, racial discrimination, equal opportunities, national identity and political participation of minority groups within a framework of Welsh governance and social policy in Wales
- Childhood and youth studies, particularly sexuality, gender and race in education and in popular culture
- Representation and asylum
- 'Mixed race' children in care
- Community care and the development of inclusive communities
- Intergenerational relationships, housing and migration of older people
- Refugee nurses
- Education and South Asian young people
- Islamic Law
- Religion and the Environment
- 'Race' Ethnicity and Health
- 'Race' ethnicity and mental health
- 'Race' Identity and Culture
- Transcultural healthcare
- Sickle cell disease and the thalassaemias
- BME user empowerment
- Economic regeneration, community development and sustainable health

## **Welsh NHS Health Trusts and Local Health Boards**

7.9 NHS Wales currently employs 77,000 staff, and a further 10,000 are employed in primary care. The Nursing, Midwifery and Health Visiting group is the largest, accounting for 43% of all staff. There are approximately 32,500 nurses,

midwives and health visitors, 8,500 allied health professions and healthcare/clinical scientists, and 12-14,000 health care support workers in Wales (Health Professions Wales 2005).

- 7.10 The recently established local health boards (LHB) cover the same geographic areas as the 22 existing local authorities in Wales, and LHBs and local authorities work together in planning long-term strategies for dealing with issues of health and well-being in Wales. The LHBs are also expected to work closely with their local population, inviting input and feedback on local health related matters, and consulting on any significant changes.
- 7.11 Accessing information on the research activity and service/practice models and initiatives taking place in NHS Trusts proved difficult, because of time constraints and access issues. There was more success in collating information on similar activities taking place in LHBs.
- 7.12 A number of Local Health Boards (LHBs) have initiatives focusing on BME communities, some of which include those funded by IIHF while others include projects and initiatives funded by SHARP.
- 7.13 In NHS Trusts there are a number of specialist services. These include the Sickle Cell and Thalassaemia Centre and the Multicultural Health Resources Centre, both based in Cardiff. There is also a unit dedicated to the mental health needs of asylum seekers, and a number of staff dedicated to working specifically with particular BME groups.
- 7.15 The Cardiff Local Health Board's Coronary Heart Disease and Diabetes Project (Heartlink) is funded by the Welsh Assembly Government's IIHF to offer effective treatment and advice to individuals who are at increased risk of heart disease. The Barefoot Health Workers Project, funded by SHARP, is an action research project that aims to support the health improvement of Caribbean, Pakistani, Somali, Yemeni and Bangladeshi communities in the Butetown/Grangetown areas of Cardiff. There is also a BME mental health network, supported by the Cardiff LHB, which operates from the Cardiff and the Vale Mental Health Development Project. The Cardiff LHB has also secured funding from the Big Lottery Fund to roll out a smoking cessation programme targeted at Bangladeshi and Pakistani men.
- 7.16 Newport LHB has a programme of work addressing the promotion of equitable access to services, including the identification of potential barriers such as language and communication. The Ethnic Minority Advisory Forum, a multi-agency forum facilitated by Newport LHG, is also concerned with developing appropriate services. The Community and Primary Care Nutrition Project addresses the nutritional needs of specific groups locally, including people from minority ethnic groups. In addition, there is some targeted work on specific conditions such as diabetes, including awareness days. The Heartbeat Project, funded by SHARP, supports primary health care teams working with

the Bangladeshi, Pakistani and African Caribbean communities in the Pillgwenlly and Victoria wards of Newport.

- 7.17 Swansea LHB is currently conducting a wide-ranging survey of 600 local ethnic minority communities, including Gypsy Travellers. The Asylum Seekers and Refugee Team was set up to provide accommodation and related support to 135 asylum seeker households in Swansea.

## **Voluntary Organisations**

- 7.18 Anecdotal evidence suggests that a notable amount of research has been conducted by local voluntary organisations and by regional equalities organisations, in addition to research undertaken via funding from national voluntary organisations such as the Wales Council for Voluntary Association (i.e., local mental health grants). However, for this scoping exercise, only the research activity undertaken by the following organisations was investigated:

- BME voluntary health organisations or networks.
- National social care/welfare organisations.
- National BME organisations.
- ‘Mainstream’ national organisations that have conducted research specifically on BME groups in Wales. (Note: this is a selected list based on an Internet search, organisations known to the co-applicants and responses to the questionnaires.)

- 7.19 There are two BME voluntary health organisations in Wales: Access for Black and Minority Ethnic Children and Young people (0-25 yrs) with disabilities and/or chronic illnesses (ABCD), and Awetu All-Wales BME Mental Health Group. There is one BME health and social care email discussion group ([BME-wales-health-social-care@jiscmail.ac.uk](mailto:BME-wales-health-social-care@jiscmail.ac.uk)). This e-group was established in 2002 and has 72 members.

- 7.20 Both Awetu and ABCD have undertaken research. ABCD recently undertook a needs assessment to map which services their clients (200+) were accessing and to explore their experiences of the services they used. The needs assessment data were analysed by Dr Paul Chaney of Cardiff University. The research is ongoing, and the profile of users will be analysed on an annual basis to help plan and set priorities for the year ahead. In 2002, Awetu commissioned the University of Glamorgan to conduct a study to (i) collect data from people belonging to Black and Minority Ethnic groups who have used mental health and social care services on their experiences of these services; (ii) collect data from mental health professionals, managers and commissioners; (iii) raise awareness to empower communities to access appropriate services that are available; and (iv) provide a baseline of evidence for planning to identify, monitor, and address mental health inequalities. Awetu worked closely with the university throughout the study, and has now drafted a comprehensive action plan based on the findings. This is part of the organisation’s three-year business plan.

- 7.21 There are five national BME social care/welfare organisations: All-Wales Ethnic Minority Association (AWEMA), Black Voluntary Sector Network Wales

(BVSNW), Council of Ethnic Minority Voluntary Organisations (CEMVO), Minority Ethnic Women's Network (MEWN), and the All Wales Saheli Association. The Black and Ethnic Minority Support Team (BEST) is a partnership of four national organisations (MEWN, BVSNW, AWEMA, and the Scarman Trust) established to provide support to Black and Minority Ethnic communities and organisations within the scope of the Communities First Programme. Also important is the work of Black Women Stepping Out Ltd (BAWSO), an organisation providing services for BME women all over Wales (and beyond) suffering domestic violence.

7.22 All the above organisations/partnerships are research active. Research recently conducted includes

- Improving access to advice services (MEWN Cymru)
- Health awareness project for BME women (MEWN Cymru)
- Supporting BME communities and organisations within the scope of the Communities First Programme (BEST)
- Hidden needs of vulnerable BME women (BAWSO, MEWN Cymru and Tai Hafan)

7.23 There are also a small number of 'mainstream' national organisations with a specific BME stream or service. These include Newlink Wales, a national drugs and alcohol misuse organisation, and SNAP Cymru, a national voluntary organisation that offers information, advice and support to families of children and young people who have, or may have, Special Educational Needs and/or disabilities. Newlink Wales has undertaken research into the information and treatment needs of the Somali community in Cardiff.

7.24 In this scoping exercise, two national 'mainstream' organisations were identified as having conducted research specifically on BME groups in Wales. Diabetes UK Cymru conducted a programme of research on the health promotion needs—and, crucially, some promising ways of meeting these—of minority ethnic communities in Wales. The programme was led and managed by Diabetes UK Cymru, with funding from the National Assembly for Wales and GlaxoSmithKline plc. The Uncertain Futures Study is a research collaboration between Children in Wales and two south Wales universities (Cardiff University and the University of Glamorgan): it provides an analysis of the numbers of asylum-seeking children in Wales, and highlights the major issues affecting their lives. It also reports on the people working closely with them. The issues covered include social integration, immigration processes, some encouraging aspects of service provision, and areas of concern relating to education, health, housing and social care. The report was published in February 2005.



## 8 THE RESPONSES TO THE STAKEHOLDER QUESTIONNAIRE

*Objective Two:* To identify the perceived research priorities, the barriers and the opportunities for developing this theme as understood by potential network members and their constituents.

8.1 The questions asked in the questionnaire were as follows:

- What do you think are the key health and social care issues affecting BME groups in Wales?
- Please list the issues you have identified in terms of importance.
- What are the key challenges affecting research on the health and social care of BME people in Wales?
- We are seeking to establish a research group or network to take forward the issues raised in this questionnaire. What value would this have for you or your work? What would you want from such a network?
- How would you suggest we take this forward?

8.2 Each co-applicant was asked to send out questionnaires. Questionnaires were also sent to various networks and consortia. E-mail discussion managers were asked to post the questionnaire (and accompanying documentation) to their members.

8.3 One hundred and forty-two questionnaires were returned. The table below shows the targeted stakeholder groups. The responses reflect the perspectives of the different stakeholder groups, and a good deal of common ground in identifying needs and ways forward. Roughly one-third of the 142 respondents identified themselves as having a BME background/heritage.

**Table 3 Responses from stakeholders**

Stakeholder Group	Number of responses
Staff – Voluntary sector	28
Service users – Voluntary sector	29
Staff – NHS Trust	19
Staff – Welsh University	37
Staff – Local Authority	8
Staff – Local Health Board	6
Staff – Equalities organisations	5
Community groups	2
Other	5
<b>Total</b>	139*

\* data missing from 3 questionnaires.

### 8.4 Analysing the questionnaires

Conceptual or thematic analysis is commonly referred to as a method of establishing the existence and frequency of concepts or themes, most often

represented by words or phrases in a text. Co-applicants and focus group facilitators conducted a manual, thematic analysis of the questionnaires and the summaries of the focus group discussions. The summaries of their findings were presented at the final meeting of the group. At this meeting, one summary of the overall findings of the canvassing work was drafted. During this meeting, it was decided that the prioritising of specific health and social care areas, and the listing of specific clinical research priorities, should be done after further consultation and engagement. The rest of this section provides excerpts from the summaries, as well as direct quotes and free text bullet points from the dataset, which has been organised according to the key questions asked.

## **Key health and social care issues affecting Black and minority ethnic groups in Wales**

8.5 This question received the greatest volume of response. Views on the key health and social care issues affecting Black and minority ethnic groups in Wales may be grouped within nine broad themes:

- Illnesses throughout the life course
- Broader determinants of health and well-being
- Access to services
- Service delivery and quality of care
- The role of equalities agencies and BME voluntary organisations
- Regional factors to be considered
- Ethnicity data
- The health and social needs of specific population groups
- The importance of an R&D infrastructure

### **8.6 Illnesses throughout the life course**

- Many respondents were concerned about the specific illnesses that are known to affect certain BME groups to a disproportionate extent. These include coronary heart disease, hypertension and stroke (cerebrovascular disease), diabetes, cancer and the haemoglobinopathies (sickle cell disorders and the thalassaemias).
- Mental health, in particular depression and emotional problems, was also identified by several respondents as a cause for concern. Mental illness, along with conditions such as sexually transmitted infections, is amongst the more culturally complex areas presenting a challenge to services, and requiring particular sensitivity.
- Other specific health concerns raised were obesity, dental health, reproductive health, sexually transmitted diseases and communicable diseases (e.g., tuberculosis, HIV and AIDS), infant feeding practices, smoking rates in some BME communities, conditions associated with Vitamin D deficiency, as well as drug and alcohol misuse (including khat and paan chewing).
- Also highlighted was the need to be able to monitor regional and national trends across the life course, from children's to older people's health and social care needs. As one respondent noted, the 'health care needs of ethnic

minority groups may be slightly higher than for the indigenous population. However, there is no systematic or detailed evidence available about the health of ethnic minority elders'. The needs of BME elders and women in their middle years are poorly understood, and information about different points in the lifespan generally needs to be fuller to embrace a diverse range of cultures and beliefs.

- With regard to well-being support throughout the life course, it was pointed out that nursing in residential care requires a better training framework in relation to the increasing diversity of the Welsh population. It was felt that intergenerational issues within different ethnic groups are not always understood by providers, and may be the subject of stereotypical beliefs.
- The low uptake of screening services was also considered an important issue of concern.

#### **8.9 Broader determinants of health and well-being**

- Responses covered social needs such as housing, poverty and education, which have proven links with health and well-being. Several people noted the effects of poverty, and the complex relationship between minority status, tacit exclusion from the job market (particularly for women) and health and well-being (including mental health and isolation).
- Racism and the perception of racism were widely identified as factors in creating exclusion from mainstream services.
- The relationship between 'race', ethnicity, gender and social class was also identified as a factor in the social exclusion of BME groups that can lead to a negative impact on health status. For some respondents, racism or discrimination lie behind the unwillingness to make appropriate service provision for all people in Wales.

#### **8.10 Access to services**

- The accessibility of services, information about available services and the perception that services were neither appropriate nor responsive to the needs of diverse populations were all considered to be severely hampering the overall health and well-being of this population group.
- There was a 'need for useful and appropriate health promotion programmes'.
- With regard to language services, both translation and interpreter services were named by almost every respondent as a key barrier to accessing services and health information.

#### **8.11 Service delivery and quality of care**

- 'As with the non-BME population, the "issues" in health and social care are that information, support and expert practitioner help are not always available in the most appropriate manner which is sensitive to and addresses the social, economic and cultural needs of members of BME communities.'
- The dominant view was that there was a need to enhance staff knowledge and develop cultural competencies (individual as well as organisational).
- Dietary knowledge was thought to be of importance, as were questions around the interpretation of symptoms and understandings of illness. Both these areas are sometimes linked to religio-cultural beliefs, as are different approaches to medicine described as 'traditional' and bio-medical.

- The issue of awareness of difference was expressed in such terms as ‘xenophobia’ amongst health and care providers. There was a need for ‘multicultural awareness by service providers’. Terms such as ‘culturally appropriate’ and ‘culturally sensitive’ services were used frequently. The general consensus was that patient-centred care could not happen until staff, working in all sectors, took on board multiple needs. ‘The “one size fits all” approach did not work. There remained the need for an all-systems and corporate-driven change.’
- Several respondents made staff training and awareness raising in BME issues a priority, but it was also pointed out that the time allocated for these activities needed to be protected, and the subject given greater status within existing training courses. The quality of existing training was brought into question.
- Many thought that greater awareness was needed to enable a greater quality of communication and engagement between communities and service providers.
- There was a need to build on research in order to develop practice models and services (‘research is relatively cheap: improving services is expensive’).

#### 8.12 **The role of equalities agencies and BME voluntary organisations**

- A clear message from the BME mental health services users who responded was that, as one wrote, ‘there are not enough Black organisations in Wales that work in health and social care. There is also a need for BME service user groups’.
- One respondent commented on the number of voluntary agencies conducting research:

The ‘aim’ should be to root R&D in the priorities of BME specialist organisations so that joined-up working can take place and that consultation can be a two-way rather than the usual one way – top down – exchange. Moreover, these voluntary agencies are key access points to BME groups and will have invariably built their priorities on the basis of the needs of their constituents. The work of established regional and All-Wales health and social care organisations, in the initial stage at least, should be used to inform the network’s research strategy.

- The constraints on the BME voluntary sector were highlighted (‘although voluntary and community organisations provide services ... they cannot provide for all sub-groups, they are under-resourced and unlikely to be able to sustain services’) as was the inaccessibility of many generic voluntary services. Also highlighted was the fact that some mainstream services were making efforts to make their services more accessible.

#### 8.13 **Regional factors**

- Very little is known about the situation of BME people in virtually all-white areas. This is an issue not just for rural Wales but also for most urban areas outside of Cardiff, Newport and Swansea.
- From the focus groups, it is clear that there are different challenges and research priorities in the three regions. For instance, only in north Wales were health and social concerns concerning migrant workers considered

important. In north Wales, the issue of being ‘over-reached’ was raised in the context of the comparatively small and widely dispersed BME population. Although it was highlighted in the two focus groups in south Wales, the issue of being ‘over-reached’ was raised in the context of the research process and the consultation models used. Mid Wales presents another challenge, because of the scarcity of collated information on the target population in general, with less known about its health and social well-being.

- The funding bias was also noted, with the need to put more funding into north and mid Wales.
- The effect of ‘locking groups into policy fields’ was seen as an issue in the three regions generally, as was the impact this can have on providing support and help to particular BME groups.

#### 8.14 **Ethnicity data**

- The lack of useful ethnicity data was another key challenge. This issue was put succinctly by one respondent, who wrote:

In order to plan services effectively, demographic and health-profiling information on the BME communities in Wales should be collated and made available. Ongoing national, regional, as well as ward and neighbourhood level profiling work is necessary. Presently there is a dearth of statistical health data on BME groups. Reliable data on ethnic groups and ethnic monitoring are essential tools for ascertaining the ... health care needs of a population, as well as for monitoring current services and commissioning new services.

- Also considered problematic was the ‘the amalgamation of Welsh data with English data to produce “England and Wales” data – wholly unacceptable in the era of post-devolution policy-making’.

#### 8.15 **The health and social needs of specific population groups**

- For asylum seekers and refugees, unfamiliarity with health and social care provision in the UK and difficulties in accessing services/healthcare were cited as issues of particular concern, particularly in areas where there were few minority ethnic communities. Additional health and well-being problems were recognised, including post-traumatic stress disorder, malnourishment and disabilities.
- In the case of gypsy and traveller groups, the issues of poverty, homelessness and the threat of eviction from sites, and the lack of sites to reside on, were all raised. For both groups, racial discrimination and institutionalised racism were also important concerns.
- Anecdotal evidence indicated that there were close to 10,000 migrant workers in north Wales. Housing, social welfare, employment issues (i.e., impingement of rights, harsh working conditions and mobile, short-term contracts), difficulties accessing childcare arrangements and not getting support were some of the problems affecting this multi-ethnic group. Other issues included lack of knowledge about health and social care, as well as the education system. Another important point was that the dominant perception of the ‘lone worker’ was problematic, as there existed in north Wales families of migrant workers.

- Of particular importance were the needs of BME women, and the role of female doctors and care workers for some BME women.

#### 8.16 **The importance of an R & D infrastructure**

- Included in this theme was the need to conduct research into the health of BME groups on a regional and All-Wales level, to gather and collate relevant research findings, and to ensure that these datasets, information and best practice were kept up to date. As one respondent wrote:

I feel it is well and good to carry out research, but I would like to see the information collated being fully utilised. In my experience people are getting fed up of being asked questions time and time again about barriers and lack of services, but nothing ever gets any further than that. I feel it is vital that the research and information collated should make positive changes in the health and social care services.

- Linked to this was the need ‘to build a greater understanding of how to conduct research on BME health and social care issues’. Questions were raised not only about a skills or capacity deficit in this area of research, but also about the funding of research and the prioritisation of the relatively small number of BME groups in Wales. Questions were also raised about the influence such research might have on policy, as real change would be likely to encourage interest and participation.

### **Key challenges effecting research in this area**

8.17 We grouped the responses to what respondents considered to be the key challenges effecting research on the health and social care of Black and minority ethnic people in Wales within the following five broad themes:

- User involvement and public participation
- Community engagement
- Sustained funding
- Workforce development and training
- Mainstreaming of the equality agenda

#### 8.18 **User involvement and public participation**

- There was a broad consensus that BME people should be involved in the nomination of research agendas, and should have a say in the way research is conducted in their communities. The use of participative methodologies was suggested as a way forward.
- Some respondents perceived a lack of interest or willingness to engage with research on the part of BME groups, and a reluctance to share information with people outside their community because of unease or suspicion about the purposes of the research.
- The issue of the usefulness of research was also highlighted, as one respondent succinctly explained: ‘the main challenge is the brokerage of research data between acceptable output parameters required by health and social care methodologies and the completely different set of input values

from the BME community. The translation is a non-trivial matter and difficult ...’

- The overall thrust of user involvement seemed to wish to engage BME communities in decisions about the investigation of their own needs; to determine authentic priorities for research; and, lastly, to gain access to information in order to fine-tune policy and action.

#### 8.19 **Community engagement**

- The overwhelming consensus was that there was a need to involve communities and users in priority-setting at each stage of the research process. There was a need to find ways ‘to engage with BME people in a meaningful way in order to collect accurate data’.
- The perception of being ‘over-reached but under-valued’ in the implementation of improvements in care, or the commissioning of new services, was a real challenge, with consultation/research fatigue giving way to disillusionment.
- Other challenges were the research capacity, experience, language skills and motivation to investigate the needs of BME populations in Wales, and the process of feeding research into policy development for such a diverse population group.

#### 8.20 **Sustained funding**

- The general consensus among those who commented on funding was that there was a need to invest both time and funding. Long-term funding had to be secured. ‘The criticism of short term funding and of research that never made it to service development was strongly made (in one focus group). The proposed R&D network would need to make it a priority issue that results be followed through and disseminated to communities ... and [that] a track record is kept of WAG’s responses.’

#### 8.21 **Workforce development and training**

- Tackling how best to raise cultural competencies in the context of professional development was a recurrent theme. As one respondent wrote, ‘cultural awareness does not always lead to cultural competency. There is a need to address the education and training needs of those providing services’.

#### 8.22 **Mainstreaming of the equality agenda**

- There is a need to ‘highlight the mainstreaming of the equality agenda as a way in which to keep the issue of ‘race’ and ethnicity on the agenda’.
- The network may also need to considering forming a ‘pressure group to ensure that research that it considers to have important implications for BME communities in Wales is actively considered, implemented, or if not, good reasons are given for not doing so’.
- It was suggested that BME issues should receive priority within health and well-being strategies, to ensure that the inclusiveness of services is acknowledged at planning levels.

## **What stakeholders would want out of the proposed network**

8.23 Taken together, the following key phrases and bullet points indicate some of the key expectations and needs of the stakeholders.

### **What Stakeholders want: For the network to be of value to BME patients, groups and communities**

- Part of the value indicated for BME people was in highlighting the areas requiring work, with a view to improving services and addressing areas of inequity.
- ‘(I)t would help social conditions improve.’
- The question of mainstreaming BME needs within the general ranges of service provision was suggested as an outcome of such a network.
- A ‘place which would be comfortable for BME people to be associated with as well as attending very closely to the needs and voices of BME people’.
- ‘It’s time to see improvements.’

### **What Stakeholders want: Development of a research infrastructure**

- Joined-up research infrastructure: ‘to be honest, I do not have a good enough sense of the macro-level picture’.
- From ‘a health voluntary agency perspective, there is a need to be able to have access to Welsh-based documented evidence covering key areas (i.e., mental health) so as to build and enhance services’.
- ‘Creating such an infrastructure would be timely and useful. An up-to-date list of contacts and bulletins of ongoing research and findings would be very useful.’
- To build and take action on the research that has already been conducted.
- Have funding allocated to carry out further research and act on recommendations.

### **What Stakeholders want: Access to resources**

- The network could be structured to ensure a system for reporting key findings, with emphasis on dissemination and application to all stakeholder groups.
- ‘I would want a central resource which can be accessed to help with writing funding applications, peer reviews of reports, and articles for publication.’

### **What Stakeholders want: The opportunity for joined-up working**

- That the information collated is used as a bridge between service users and agencies.
- ‘I would hope that our views would be sought on a regular basis and that the group could address problems or issues that arise locally. If nothing else, that would help us to track the problems that people face and possibly look at what the commonalities causing these problems were.’

### **What Stakeholders want: Service development**

- Implementing strategies and frameworks to develop the required services
- ‘To support the strategic development of public services in north Wales’
- Training on how to conduct research from a user or voluntary-sector perspective

## **8.24 Suggestions of ways forward**

Taken together, the following key phrases and bullet points provide an indication of possible ‘next steps’ in developing the proposed network:



### **Ways forward: Engagement and consultation**

- ‘Talk to lots of people. Ensure ownership by the right people.’
- Hold consultation workshops, quarterly meetings and annual information days.
- Form a reference group with representatives from all the different groups to plan the development of the network.
- ‘Secure representation on key health and social care government and regulatory bodies and committees.’
- There is a need for further consultation work, making sure there are single-sex meetings as appropriate.

### **Ways forward: Focus on key improvements to services**

- ‘Make sure that research has impact at point of delivery’
- Staff education and active recruitment from under represented groups
- ‘In rural Wales, to actually establish the numbers of minority groups and their problems, to raise awareness, would be a good first step’

### **Ways forward: Develop the infrastructure**

- Gather data of projects completed to date.
- Database of people working in health and social care with list of skills.
- Form groups with similar subject areas and research priorities.
- ‘Local working parties could be set up and feed into larger groups. The larger groups could actually be part of an ongoing research group which not only highlighted issues, but were able to work towards resolving these issues. This would maintain the momentum within communities and would lead to a more proactive BME group that focused on health issues.’

## **9 RESEARCH AND DEVELOPMENT ACTIVITIES OF ESTABLISHED NETWORKS AND CENTRES IN THE UK**

*Objective Three:* To place the work of the proposed network in a wider context, by scoping the research and development activities of established UK networks and centres with a similar remit.

- 9.1 Research on the health of BME groups has gone through a number of phases: (1) interest in the unusual (‘exotic’) diseases of ethnic minority people, (2) the impact of their culture on their health, and (3) comparing the patterns of diseases with those of the majority white populations. More recently, there has been interest in (4) the impact of poverty and socio-economic deprivation on health, and (5) how best to adapt health care policy, research and services to meet the needs of a diverse population.
- 9.2 There remain major areas in which knowledge about the health of BME groups in Britain is either substantially lacking or fragmentary. Despite the large number of small, local studies, only since the early 1990s has a national picture of the health of BME groups begun to emerge. This was primarily a result of the 1991 Census,

which for the first time asked a question on ethnicity. This was followed by national surveys targeting BME groups, conducted by the Department of Health and the Policy Studies Institute in England. Health and social care research has gained momentum, with the increased recognition of the importance of significant health inequalities, notably following the Acheson Commission (1998).

- 9.2 The existence of the academic Centre for Research in Ethnic Relations (CRER) (formerly, the Research Unit on Ethnic Relations) was the catalyst for the development of a sub-discipline that spanned traditional academic and professional groups, and provided the first master's level degree. Subsequently, a number of other centres have been established.
- 9.3 Five major academic centres in England, and one in Scotland, are active in the field of 'race', ethnicity and health. They are as follows:

**Centre for Evidence in Ethnicity, Health and Diversity (CEEHD)**

An ESRC-funded joint centre linking the work of the Mary Seacole Research Centre at De Montfort University (Leicester) and the Warwick University medical school (Coventry). The centre is building on the earlier work of CRER. The NHS National Knowledge Service (or National Electronic Library for Health) has recently appointed CEEHD to manage a Specialist Library (i.e., website) in ethnicity and health, which will provide a central core of information and quality assurance.

**The Mary Seacole Centre for Nursing Practice at Thames Valley University**

The Centre specialises in nurse education. The resources this Centre generates are, however, also used by other professions. Research activity includes studies of sickle cell and thalassaemia, and programmes to attract BME people into nursing. The centre is linked to the educational activity of the Royal College of Nursing, and it played an important role in the development of the online course in Cultural Competence and Nursing launched in April 2004.

**The Middlesex University Centre for Transcultural Studies in Healthcare**

This Centre is well established and is linked to other 'race/ethnicity' research activity in the same University. The focus is largely on nursing, but a number of detailed studies of communities and disease-specific needs have been carried out in conjunction with local community-based groups. The Centre manages an international European electronic network of researchers and practitioners in Transcultural Care, and links to a European network of transcultural nurses.

**The Centre for Ethnicity and Health at the University of Central Lancashire**

The Centre has developed a large number of projects and has a strong track record in drug and alcohol work and mental health issues. Staff members work closely with central Government bodies. At present the Centre does not have a dissemination arm.

**The Centre for Primary Care Research**

This Centre is part of the Nuffield Centre at Leeds University Medical School. The Centre has developed a strong portfolio of research around multi-cultural practice, including sickle cell/thalassaemia and disabilities (notably deafness and

learning disability). Current activities include hosting a network of trainers in ethnicity and diversity, managing an electronic discussion list, and producing newsletters and other publications.

#### **Ethnic Minority Resource Centre (Scotland)**

In 2003, a new special health board was created, by bringing together the Public Health Institute of Scotland (PHIS) and the Health Education Board for Scotland (HEBS). The National Resource Centre for Ethnic Minority Health is set up within PHIS to support NHS Boards in meeting the expectations laid down in the recent Health Department Letter from the Scottish Executive. The Resource Centre has a part-time director, Dr Rafik Gardee, and three project managers working in the areas of policy, information and training

- 9.4 There are also a number of networks, units and services that have a particular interest and track record in work of relevance to this proposed network. They include

The Race Equality Unit (now REU), formerly part of the National Institute of Social Work. It continues as an independent research centre, specialising in social care issues, especially those relating to age and disability.

The Leicester Centre for Ethnic Health Research is a local regional alliance of Universities and NHS Trusts, based on the University Hospitals of Leicester and the Leicester Primary Care Research Alliance. It supports local research and development, with a focus on clinical practice. Current topics of interest include cancer, child health, diabetes and associated conditions, genetics, rheumatology, kidney disease, and the development of an 'expert panel' of community-based advisors for health care research.

The Policy Research Institute on Ageing and Ethnicity (PRIAE) is an independent organisation with a significant portfolio of work relating to age and ethnicity or 'race'. It works across Europe in the context of 'age and migrant populations'. It also produces educational materials and conferences.

Information Centre for Asylum Seekers and Refugees (ICAR) and Health for Asylum Seekers and Refugees Portal (HARP) are groups/ centres specialising in the requirements of new migrants: more specifically, refugees and asylum seekers.

Ethnic Research Network is a network of BME researchers, not specifically related to health and social care, but providing access to a large number of concerned and qualified researchers.

The Centre for Research into Ethnicity in Mental Health, is based at the Warwick University Medical School and supported by the National Institute for Mental Health in England (NIMHE).

### 9.5 **Survey Findings**

Staff at CEEHD circulated a short survey to the identified academic and community-based research centres in the UK. The following questions were asked:

- Name of Centre / Role of Person responding
- Main Organisational or Funding source of support for your Centre
- What was the rationale for establishing this particular Centre or activity? (What is your 'unique contribution' or area of specialist interest?)
- What are the advantages and disadvantages of 'stand alone' or specialist units in research in the area of health and social care for minority groups?
- How do you make sure that research findings (and any other services you offer) are 'mainstreamed' and disseminated into UK policy and practice and equality debates?
- How have links (if any) been developed with BME patients, service users or groups?
- Do you have any 'best practice' guidance? If so, please attach it, or indicate where to find it.

The survey findings are based on analysis of the eight responses received. The rest of this section provides excerpts from the summary provided by CEEHD, which has been organised around the questions that were asked.

### 9.6 **Justification or rationale underpinning the development of the centre or network**

In nearly every case, the rationale for setting up the centre was the perception that no other organisations or centres offered co-ordinated research programmes, policy work or support in the area of primary interest, whether a medical condition (e.g., the haemoglobinopathies) or a field of care (e.g., health of BME older people).

### 9.7 **The generalist versus specialist debate**

There was no clear solution to the dilemma of being specialist or generalist, stand-alone or integrated. Most respondents felt that there was a need to have identifiable centres of expertise associated with particular issues, so as to make it easier for people to know where to turn for advice. Linked to this was the issue of the flexibility and the ability to build trusted relationships with key players and communities. Being a specialist centre or unit also meant that there was a constant need to make links with and contribute to 'mainstream' research and professional developments.

### 9.9 **Funding**

None of the centres had secure long-term funding. The majority were based either in universities or community organisations, and were supported by individual personal inputs, project grants and competitively funded research bids, and some central government or Primary Care Trust (PCT) grants for specific activities. Some community-based projects had secured set-up funding from Lottery sources.

**9.10 Improving the health and social well-being of targeted population: From Research to Practice**

Every centre placed a high value on dissemination. It was noted, however, that this activity was hindered by resource constraints, and the requirement to move on to new projects while awaiting the action of those who commissioned the work. Political will (not necessarily party-political), among policy makers and executive bodies, was crucial in ensuring that results had an impact on policy and practice. However, the majority of centres stated that they also worked closely with community groups, and placed a high value on making presentations at conferences and workshops, and on producing materials in accessible formats. There was also extensive use of the Internet, including websites, discussion lists, and active linking with Department of Health/NHS and with those undertaking University-based research.

**9.11 Links with service users and communities**

Links with service users and communities were in every case the result of long-term development and the building of trust and respect—and often derived, at least originally, from the work of key individuals. There were few shared networks. Centres based on service delivery projects had used outreach staff and created appropriate resources for their communities of interest. Other important links included collaborations with the small number of BME community-based disease-specific voluntary organisations.

**9.12 Best practice or guidance**

Best practice or guidance documents were emergent priorities, but there were few established procedures. Centres and individuals were willing to share their experiences, and to discuss or support new initiatives that might lead to overall implementation of better practice that met the health and social care needs of minority ethnic groups and reduced inequalities.

**9.13 Working with other Centres and Networks**

Collaborative working was generally seen as desirable. There was increasing interest in the development of training for professionals, registers of researchers, and preparation of guidelines for service delivery. Work is needed to build relationships between members of individual centres, and awareness of each other's potential contribution. Other relevant issues included sharing best practice and established resources, and working together with mainstream policy makers and professionals to ensure a greater awareness of the established issues, centres and resources in the UK.

## **10 THE SCOPING STUDY - COMMENTARY**

- 10.1 The BME population of Wales is not a single entity with a unitary set of needs (any more than the white population is). Moreover, in many ways the health and well-being needs of BME people are no different from those of the white majority ethnic groups, since respect for beliefs and lifestyle, decent income and housing, good quality services and personal safety are considered important factors in the health and well-being of all people. One key factor distinguishing the health and social care needs of BME groups from the majority white ethnic groups is, however, the fact that they face an extra layer of barriers rooted in real and perceived social, cultural and ethnic differences, and a legacy of exclusion, marginalisation and racism.
- 10.2 The framework for health and social care services in Wales is flexible enough to address the multiple challenges of providing care to an increasingly diverse population. The scoping study has sought to provide a 'snapshot' of the current work underway, and to begin to map out the areas that need to be developed from an all-Wales, multi-sector and interdisciplinary perspective.

### **Research activity in Welsh universities, NHS Trusts, Local Health Boards and Voluntary Organisations**

- 10.3 The development of research strands is encouraging and highlights pockets of expertise. These strands remain, however, isolated from one another. High-level research is being conducted, but the dissemination of research, and its entry into the practice environment, are not evident. 'Stand alone' research activities account for the majority of current research activity. 'Stand alone' studies cover a number of areas in health and social care. In many cases, the studies conducted by universities covered a specific region. Not one all-Wales study with a fully representative sample of BME participants was found.
- 10.4 Although the majority of the 65 research-active academics we found in this review are based in universities in south Wales, academics in all nine Welsh universities are active in research in this cross-cutting theme. There are senior-level academics researching in the areas of nursing, health studies, biomedical and clinical research, and in social welfare, equalities and social policy. It is important to note that Paul Ghuman, who is based at the University of Wales, Aberystwyth, was awarded a personal chair in Ethnic Minority Education in 1998. Despite collaboration between academics, isolationism, the duplication of research, and ignorance of the research taking place in other universities are severely hampering the development of this subject area.
- 10.5 Research is becoming important for voluntary sector organisations. The review of voluntary agencies engaging in research in this subject area makes clear that there are an increasing number of voluntary sector-university collaborations. Local health boards, health divisions of the Welsh Assembly, and UK funding bodies are providing funding, but primarily for fixed, 'stand alone' projects. If we were to base the network's research agenda on the priorities highlighted by

the work of the national Equalities agencies, and by national BME health and social care voluntary organisations in Wales, they would be as follows:

- Mental health
- Drugs and alcohol misuse
- Children and chronic illnesses
- The health needs of women (including those suffering from domestic violence)
- Mainstreaming race equality
- BME community development and empowerment
- The health needs of asylum seekers and refugees

10.6 During this scoping exercise several ‘mainstream’ organisations expressed the desire to find ways to make their services more responsive and accessible.

10.7 Much more work is needed in order to chart the research activity currently taking place in NHS Trusts, local health boards and social service departments.

### **Responses to Stakeholder questionnaires**

10.8 There was a high level of synergy between the rationale outlined for this network and many stakeholders’ views on the key health and social care issues affecting BME groups. There was also a high level of synergy between the rationale outlined for this network and many stakeholders’ views on the importance of paying attention to the needs of the health and social care workforce, and of underpinning the work of the network in a BME user, community and public engagement agenda. The importance of regional differences and priorities, and the need to develop the infrastructure of the proposed network, must be developed in future work. The importance of putting in place a framework in which to monitor health and social well-being trends, and to collate useful ethnicity data, was also highlighted as a key area that needs to be developed. In summary, there is an awareness of the importance of addressing the multiple needs of BME groups, a general idea about the challenges, and a willingness on the part of the stakeholders to work together.

### **Research and development activities of established networks and centres in the UK**

10.9 The exercise conducted by the Centre for Evidence in Ethnicity Health and Diversity (CEEHD) highlights the fact that in England at present there is no established and centralised source of best practice guidance and evidence, or of established standards and professional support. As highlighted above, attempts at local and regional level in England to develop networks and establish groups to share information and best practice have, for a number of reasons, been short-lived. This presents a unique opportunity for developing a network in Wales that is not only rooted in the needs of the Welsh population, but also has the potential to provide services and expertise on a UK-wide and international level.

10.10 The scoping study makes clear that there is a need to establish a network or unit to cover the health and social care needs of BME groups in Wales. Moreover,

there is a ‘critical mass’ of key stakeholders across the health and social well-being sectors, and there is evidence of the need for co-ordinated activity to develop the necessary infrastructure and knowledge of this small, diverse and increasing population.

## **11 RECOMMENDATIONS: OUTLINE PLAN FOR ESTABLISHING A NETWORK**

11.1 This final section provides a framework for a Health and Social Care R & D Plan covering Black and minority ethnic groups in Wales.

11.2 The proposed network presents an opportunity for a focused, co-ordinated and cross-sector programme of research and development, dedicated to issues of ‘race’, ethnicity, health and social care in Wales. The aim will be to establish a network that can be accessed by medical and health professionals, BME patients and members of the public, and those in the voluntary health and equalities sectors, the local authorities and social services. The proposed network will enable regional and All-Wales research to be reviewed and prioritised, in order to build on the plethora of local studies and needs assessments. It will provide a dedicated R&D context in which to link issues of ethnicity and ‘race’ to the key biomedical, clinical, and health care research underway, so as to broaden the knowledge base of the appropriate clinical models and practice frameworks needed to care for diverse population groups.

### **11.3 Framing considerations shaping this network include**

- An embryonic level of statistical ethnicity data currently available
- A moderate and increasing level of research activity rooted in the nation’s key health priorities, but as yet isolated
- An embryonic level of research activity specifically addressing ‘special concerns’ such as sickle cell disorders, the needs of refugees and asylum applicants (i.e., post traumatic stress disorders)
- A ‘critical mass’ of key stakeholders across the health and social care sector
- An increasing interest in research and development activity in BME specific, as well as in ‘mainstream’, voluntary agencies
- An embryonic level of joined-up user, community and public engagement work
- No centralised support and information centre, unit, or service covering key health and social care concerns facing ethnic minority groups in Wales

### **11.4 Proposed aims of the Network**

It is envisaged that the proposed network will establish a research and development programme rooted in the following six core aims:



1. **To establish a multidisciplinary research infrastructure** capable of identifying the health and social care priorities of BME patients, service users and groups in Wales.
  2. **To develop high quality evidence-based research strands** with local, regional and All-Wales outputs. The strands to be developed will be rooted in the health and social priorities of BME populations in Wales.
  3. **To give specific attention, and make a substantial contribution, to BME community development and engagement** by working with groups to make improvements to their health and social well-being, and by proactively and systematically seeking improvements to their care in the health and social care sector. Equally important is the need to embed the work of this network in research methodologies that seek to build research capacity within BME community groups, in order to facilitate health improvements, foster empowerment and encourage higher levels of engagement with health and social care services.
  4. **To give specific attention to the Welsh health priority areas and health improvement programmes** by offering a gateway for the exchange of information, and for research collaborations with all the research networks to ensure that the health and social care needs of BME patients, service users and groups are clearly evidenced in the research that is undertaken in all the networks.
  5. **To utilise research findings to define practical solutions that assist both health and social care commissioners and service providers, BME patients, service users, community groups and organisations**, and other networks and key groups within the research and development infrastructure in Wales and beyond. This aim is rooted in the need to be able to make an informed contribution to the development of local, regional, national, UK and international policies that integrate research generated by the network into key public, private and voluntary sector health and social care practices and services.
  6. **To ground all activities in an appropriate network model.** Rooted in this aim is the need to work proactively on the infrastructure of the research network, to ensure that it operates as an effective and important conduit of information related to the health and social care of BME groups in Wales.
- 11.5 The plan we recommend here is ambitious; however, the challenges are great. Structured around the six core aims of the proposed research network and key dimensions of network design, the strategic aim of this three-year development plan is as follows:

*To establish a multi-discipline, cross-sector networked system of collaboration and co-operation in order to create an environment in Wales for debate that connects academic research with user, community and public development whilst impacting on the policy and practice of local, regional and national health and social care organisations at key levels.*

11.6 Based on the findings of this study, the required features of this proposed network will include

- All-Wales networked and multi-sector approach to health and social care improvements
- A view of the need to tackle the wider determinants of health and social well-being
- Emphasis on evidence-based approaches at both policy and service level
- Emphasis on enhancing the clinical research environment, targeting specific conditions
- Emphasis on the Welsh Assembly Government's health and social care priorities
- The rooting of the network in the priorities of existing voluntary health, social care and social welfare organisations
- Service user empowerment and involvement
- Examination of the methodology and process of community engagement
- Dissemination strategies and health promotion work
- Emphasis on building up the research workforce in all the targeted sectors
- Secured funding, with a funding strategy developed in order to ensure long-term sustainability and growth
- Links with other research and development networks and with specialist centres with similar remits in other parts of the UK and beyond
- Clear accountability arrangements, a business plan, a research and development strategy, and a community and public engagement strategy

11.7 The following table provides a broad overview of some of the action points that will be considered in future development work.

Core Aim	Key action points to be considered
<p><b>To establish a multidisciplinary research infrastructure</b> capable of identifying the health and social care priorities of BME patients, service users, and groups in Wales.</p> <p><b>To utilise research findings to define practical solutions that assist both health and social care commissioners and service providers, BME patients, service users, community groups and organisations</b>, as well as other networks and key groups within the research and development infrastructure.</p>	<ol style="list-style-type: none"> <li>1) Draft regional R&amp;D strategies. The strategies provide the framework for the establishment, maintenance and promotion of a resilient research and development structure that is sufficiently diverse to support a range of research priorities and types of research, and is supported and developed in partnership with the key stakeholder groups.</li> <li>2) Consult widely on the proposed R&amp;D strategies, and ensure that targets are set and evaluation measures are embedded.</li> <li>3) Build up the email discussion group (<a href="mailto:BME-Wales-Health-Social-Care@jiscmail.ac.uk">BME-Wales-Health-Social-Care@jiscmail.ac.uk</a>) to operate more effectively as a vehicle for building interdisciplinary and regional collaboration in this field, in order to generate research ideas, activities and projects, foster exchanges across sectors and disciplines, and share relevant information.</li> <li>4) Establish a programme of events, bringing academics and professionals (working in healthcare, social policy, the public and voluntary sector) together, in order to enable</li> </ol>

	<p>and facilitate regular contact through seminars, postgraduate forums, workshops, research and education, dissemination and promotion.</p> <p>5) Establish a National Web Portal. This brief covers all resources, services and activities geared towards the provision of health and social care that is sensitive to the social, cultural, linguistic, and religious values and practices of Wales' diverse population. The proposed web portal will be a central access point for information, designed so that users are able to identify quickly what they need, and are shown how to access it. By identifying, describing and evaluating information, a clearing-house helps to minimise duplication of effort. As an information gateway, the BME health and social care R &amp; D web portal will minimise duplication of effort. A key feature will be extensive links to other websites.</p>
<p><b>To develop high quality evidence-based research strands</b> with local as well as regional outputs. The strands to be developed will be rooted in the health and social priorities of BME populations in Wales.</p>	<ol style="list-style-type: none"> <li>1) All-Wales review of all past research which has been conducted in Wales on this theme.</li> <li>2) All-Wales review of LHBs' and NHS Trusts' health, social care and well-being strategies, race equality schemes and local Wanless reports, in order to chart equality mainstreaming work being done. Similar review covering social services and local authorities.</li> <li>3) Work collaboratively with other networks in order to determine shared priority areas.</li> <li>4) Work collaboratively with other networks in order to support their equality mainstreaming agenda.</li> <li>5) Review research strands every three years, to ensure that the network remains at the forefront, making a significant contribution to improving the health and social well-being of the targeted populations.</li> </ol>
<p><b>To give specific attention and make a substantial contribution to BME community development and engagement</b> in the improvements to their health and their care in the health and social care sector, by consulting on the relevance of proposed research, and by providing useful and practical dissemination of research findings.</p>	<ol style="list-style-type: none"> <li>1) Draft an accompanying BME users, community and public engagement strategy. This together with the R &amp; D will shape and inform the work of the network.</li> <li>2) Compile a directory of BME organisations in Wales.</li> <li>3) Conduct work on how best to access and engage BME groups.</li> <li>4) Conduct best practice studies to inform BME voluntary and community organisations on how best to conduct their own needs assessments and help determine research priorities.</li> <li>5) Support and seek funding for All-Wales needs assessment/survey work (similar to national BME health surveys conducted in England).</li> </ol>

<p><b>To give specific attention to the Welsh Assembly Government's priority areas</b> by offering a gateway for the exchange of information, and for research collaborations with all the research networks, to ensure that the health and social care needs of BME patients, service users, and groups are clearly evidenced in the research that is undertaken in all the networks.</p>	<ol style="list-style-type: none"> <li>1) A scoping exercise to determine the needs of other networks.</li> <li>2) Establish and maintain formal links with networks and key WAG health and social care divisions.</li> <li>3) A service-mapping project to provide an up-to-date database of services available within Wales.</li> <li>4) Establish formal links with WAG Health promotion library and university libraries in the three regions, with a view to establishing a bibliographic database of references relating to identified health, social care, equalities and community health engagement work.</li> <li>5) Compilation of an Experts database.</li> <li>6) Development of training resources covering issues such as transcultural health and cultural competence.</li> </ol>
<p><b>To ground all activities in an appropriate network model</b></p>	<ol style="list-style-type: none"> <li>1) Establish terms of engagement.</li> <li>2) Develop participation agenda.</li> <li>3) Agree which network design best suits the activities to be undertaken.</li> <li>4) Explore the idea and practicalities of regional sites/satellite networks.</li> <li>5) Put in place an evaluation process of the proposed network structure.</li> </ol>

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## APPENDIX ONE RESEARCH STRANDS: WELSH UNIVERSITIES

	University	Short summary of work
1	<i>Sickle Cell and Thalassaemia (SCAT) Research Programme</i>  Genetics Policy Unit University of Glamorgan	The SCAT research programme is linked to a wider initiative to develop a research strand rooted in 'Race', Ethnicity and Health. Linked to the Cardiff Sickle Cell and Thalassaemia Centre, the SCAT programme is rooted in the following areas of research activity: <ul style="list-style-type: none"> <li>❑ Helping nurses, midwives and other health professionals better understand the two genetic disorders</li> <li>❑ Putting in place a programme that will empower those affected with sickle cell and thalassaemia to better understand and manage their treatment and care</li> <li>❑ Mapping and exploring the relevance of ethnicity, 'race' and racism and the socio-economic status of affected families in respect to service provision in Wales</li> </ul>
2	Department of Social Sciences, University of Wales, Bangor	The strand of research within the department is led by Dr. Charlotte Williams. Dr Williams' main areas of research are race, racial discrimination, equal opportunities, national identity and political participation of minority groups within a framework of Welsh governance and social policy in Wales. Coming from a background in social work, she is on the editorial board of the Journal of Social Work in Europe and has written, with others, 'Social Work and Minorities: A European Perspective' (1999). She is proactive in community organisations aimed at promoting the rights of minority ethnic groups in Wales. A leading expert, Dr Williams has written, published and presented extensively in the above areas.  Recent collaborative studies include <ul style="list-style-type: none"> <li>❑ Public Appointments: Motivations &amp; Prompts (2003)</li> <li>❑ Employment Tribunals: Decisions in Wales - A Comparative Study (2002)</li> <li>❑ Equal Opportunities Study for inclusion in the Structural Fund Programming 2000-2006 (1999)</li> <li>❑ Social Capital and the Participation of Marginalised Groups in Government (2001-2003)</li> <li>❑ Evaluation and Outcomes of Social Work Practice (1997- 2003)</li> <li>❑ Inclusivity, Equal Opportunities and the Welsh Assembly</li> </ul>
3	<i>School of Education &amp; Lifelong Learning,</i> University of Wales, Aberystwyth	<ul style="list-style-type: none"> <li>❑ Emeritus Professor Paul A.S. Ghuman has an international reputation in the field of Multicultural Education.</li> <li>❑ He has researched and published widely on issues in cognitive development, bilingualism and biculturalism and is recognised as one of Britain's</li> </ul>

		leading authorities on the intellectual development, educational attainment and ethnic identity of the UK-born Asian population.
4	<p><i>The Social Organisation of Healthcare Cluster</i></p> <p>Social Organisation of Healthcare School of Health Science University of Wales, Swansea</p>	<ul style="list-style-type: none"> <li>❑ The Social Organisation of Healthcare Cluster investigates the changing structures and processes affecting a range of health and social care organisations and user groups.</li> <li>❑ The research is sub-divided into three key themes: Changing Health Care Organisations, Organisational Boundaries, And Roles and Relationships; Social Exclusion and Marginality and User and Public Perspectives.</li> <li>❑ Professor Joy Merrell has also developed a research strand dedicated to identifying the health and social needs of informal carers within the Bangladeshi community in Swansea. She has also researched the breast health information needs of women from minority ethnic groups, and the health information needs of minority ethnic groups.</li> </ul>
5	<p><i>Ethnicity Cluster</i></p> <p>School of Social Sciences, Cardiff University</p>	<ul style="list-style-type: none"> <li>❑ The cluster comprises members of staff who have conducted research projects on ethnicity.</li> <li>❑ A review of all recent work done in this area was drafted, and this document divided the research into the following five areas: ethnicity and identity; methodological debates; ethnicity and health; racism, discrimination and disadvantage; and political participation.</li> </ul>
6	<p>Institute of Health Research Economics of Healthcare and Social Science – key theme</p> <p>University of Wales Swansea</p>	<ul style="list-style-type: none"> <li>❑ Key theme: <i>Assessment of the extent and burden of illnesses and health and social problems.</i></li> <li>❑ Research involves the assessment of health care problems and has specifically focused on areas such as mental health problems among prisoners; clients of an organisation providing housing support, and advice for people with mental health problems who are 'socially excluded' (e.g., at risk of becoming homeless, committing crimes).</li> <li>❑ It is also important to highlight the work of Professor Joy Merrell who is developing a strand of research rooted in .....</li> </ul>
7	<p><i>Centre for Islamic Law and Culture</i>, University of Wales, Lampeter</p>	<ul style="list-style-type: none"> <li>❑ The Centre covers all aspects of Islamic law and culture.</li> </ul>
8	<p><i>The Diabetes Group</i></p> <p>Cardiff University</p>	<ul style="list-style-type: none"> <li>❑ Professor D R Owens, Dr J Alcolado, Dr J Harvey, Dr J A Rees and Dr J R Peters have major research interests in the natural history of Type II diabetes; diabetic retinopathy screening; the role of the foetal environment in the development of diabetes; mitochondrial gene mutations; the aetiology of diabetic nephropathy; and alterations in vascular endothelial function.</li> <li>❑ These studies have a direct bearing on improving clinical care for patients with diabetes. In this context, it is noteworthy that Professor Owens also</li> </ul>

		works with BME community groups and community-based projects in Cardiff to raise awareness of diabetes.
9	<i>Centre for the Study of Islam in the UK</i> Cardiff University (opening in 10/05)	<input type="checkbox"/> The Centre aims to promote scholarly and public understanding of Islam and the life of Muslim communities in the UK, through high quality educational initiatives that have local, national, and international impact. <input type="checkbox"/> The Centre specialises in the inter-disciplinary study of Islam in its UK context, and particularly draws upon sociological and anthropological methodology.
10	Centre for Chinese Studies, University of Wales, Lampeter	<input type="checkbox"/> Established in 1997, the Centre offers teaching and research in the area broadly defined as Chinese Studies, especially in Chinese culture, history, media and film, philosophy and religion.

## APPENDIX TWO – STAKEHOLDER QUESTIONNAIRE AND INFORMATION SHEET

### The Health and Social Care Research and Development Network covering Black and Minority Ethnic (BME) groups in Wales Scoping Study March – April 2005

#### Background

The Welsh Assembly Government wishes to establish a series of research and development networks for health and social care in Wales. The networks will develop health and social care based research activity and enable Wales to initiate, and take part in, high quality large-scale research initiatives. Our aim is to undertake a scoping study to enhance the research and development activity in the following proposed research theme: the health and social care of BME groups in Wales.

**Research and Development remit:** The proposed network will play a key role in promoting understanding about the needs and the empowerment of BME populations in Wales through multi-disciplinary research, cross-sector partnerships, community engagement and development, and the implementation of multi-targeted promotion and dissemination strategies. It will provide the ‘joined up’ networking necessary for the cross-fertilisation of research activities and national health and social care priorities rooted in an ‘All Wales’ approach and cognisant of UK- wide research and development priorities.

**Sectors/stakeholder groups:** Welsh higher education institutions, NHS Trusts, Local Health Boards, service user and patient support groups, BME voluntary health and social care/welfare organisations and community groups, and key equalities organisations and services (such as the CRE, Equalities Policy Unit (WAG), and the NHS Centre for Equality and Human Rights).

**The Scoping Exercise:** Between 7 March and 21 April, a scoping exercise will be undertaken. We invite you to participate in the scoping exercise by sharing your



views! The purpose of this short questionnaire is to gather the views of key stakeholders, and to establish a consensus on how best to develop a network rooted in this theme. The questionnaire comprises six questions. We have also requested other information (age, gender, ethnic group or background, and stakeholder group) in order to help with our analysis. Please take a few minutes to complete the attached questionnaire.

**Further information:** This scoping exercise is being developed in collaboration with twenty-four co-applicants from across Wales, who are based in Welsh universities, Local Health Boards, national and local equalities organisations, NHS trusts, and health and social care voluntary organisations.

**The Health and Social Care Research and Development Network covering Black and Minority Ethnic (BME) groups in Wales  
Scoping Study March – April 2005**

**Instructions:** Please answer the following questions.

1. What do you think are the health and social care issues affecting Black and minority ethnic groups in Wales?
  
  
  
  
  
  
  
  
  
  
2. From the issues you have identified, please list them in terms of importance.
  
  
  
  
  
  
  
  
  
  
3. What are the key challenges affecting research on the health and social care of Black and minority ethnic people in Wales?
  
  
  
  
  
  
  
  
  
  
4. We are seeking to establish a research group or network to take forward the issues raised by this questionnaire. What value would this be to you or your work? What would you want from such a network?

5. How would you suggest we take this forward?

6. Do you have any other comments?

Please complete the following:

Age:

Gender (please tick): ☐ Female ☐ Male

Ethnic group or background:

Stakeholder group (please tick):

Service user/client – voluntary organisation ☐

Staff – voluntary organisation ☐

Staff – Social Services ☐

Staff – Local Health Board ☐

Staff member – NHS Trust ☐

Staff member – Welsh University ☐

Other ☐

If other, please specify: \_\_\_\_\_

*Thank you for your time*

## **APPENDIX THREE – SURVEY OF BME HEALTH RESEARCH CENTRES IN THE UK**

Dear Colleagues

The Welsh Office of Research and Development is exploring the value and design of a network for health and social care R&D relating to black and minority ethnic groups in Wales. CEEHD/MSRC is working with a group of organisations in Wales to support their review, and we have been asked to compile a view from ‘outside Wales’ of what happens here. We’d very much appreciate your feedback as one of the leading UK Centres for research in this field. To help structure responses, perhaps you could indicate replies to the following questions: (hard copy or e-mail replies, but as soon as possible please)

- Name of Centre / Role of Person responding
  
- Main Organisational or Funding source of support for your Centre
  
- What was the rationale for establishing this particular Centre or activity? (What is your ‘unique contribution’ or area of specialist interest?)
  
- What are the advantages and disadvantages of 'stand alone' or specialist units in research in the area of health and social care for minority groups?
  
- How do you make sure that research findings (and any other services you offer) are 'mainstreamed' and disseminated into UK policy and practice and equality debates?
  
- How have links (if any) been developed with BME patients, service users or groups?

- Do you have any “best practice” guidance? If so, please attach it, or indicate where to find it.

We would also appreciate copies of Annual Reports and details of publications, electronic discussion lists or notice boards, etc.

We shall of course circulate a copy of the final report, without indicating who said what in relation to matters of opinion: if there are any points you’d prefer us to attribute – or keep silent on – please let us know!

*Thank you for your time*

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